Research Report

Psychotropic Medication Use by Allegheny County Youth in Out-of-Home Placement

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The Allegheny County Department of Human Services (DHS) is dedicated to meeting the human services needs of county residents, particularly the county's most vulnerable populations, through an extensive range of prevention, intervention, crisis management and after-care services.

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GLOSSARY

Acronyms

CCBH	Community Care Behavioral Health, the behavioral health managed care organization for Medicaid recipients in Allegheny County
DHS	[Allegheny County] Department of Human Services

Definitions

- **Out-of-home placement:** When a youth is temporarily removed from his/her parent(s) in order to assure safety and well-being, placement can occur in a variety of settings:
  - **Congregate care** is an out-of-home placement shared by multiple unrelated individuals, where care is provided by multiple individuals not including a parent, and is intended to provide a residence of more than short-term duration. Congregate care is often referred to synonymously with institutional care, facility care or residential placement.
  - **Foster care** refers to a child's temporary home and care by a trained caregiver. The term is often used to refer to any out-of-home placement; the system is often referred to as the "foster-care system."
  - **Group home** refers to out-of-home placement in a small residential facility located within a community.
  - **Kinship care** is a type of foster care in which the youth is placed with a relative or friend of the child's family.
  - **Shelter** is typically defined as a short-term, emergency placement. Although shelter is differentiated from congregate care because of the anticipated length of stay, it has been included under congregate care for purposes of this analysis.
- **Polypharmacy:** Co-administration of two or more psychotropic medications
- **Psychotropic medication:** Drugs used to affect psychological functioning, perception, behavior or mood, typically prescribed for the treatment of severe emotional and behavioral disturbances

EXECUTIVE SUMMARY

In August of 2011, a Psychotropic Medication Workgroup was formed by Pennsylvania's Administrative Office of Pennsylvania Courts (AOPC) and charged with simplifying and improving the effectiveness of the system of behavioral intervention for children and youth in the child welfare system. A local workgroup was coordinated and facilitated jointly by staff at the Allegheny County Department of Human Services (DHS) and the Allegheny County Court of Common Pleas. The first priority identified by this group, and the focus of this report, is the frequency with which psychotropic medications are prescribed for youth in out-of-home placements.

As a first step, the workgroup held focus groups with youth and caregivers throughout the state to learn about their experiences with psychotropic medications while in a child welfare out-of-home placement. In January of 2012, three focus groups were held in Allegheny County; a total of 16 youth and eight caretakers participated. There was a great deal of similarity in the themes identified by the three focus groups, which included: 1) reactions to medication recommendation/perceived stigma; 2) lack of sufficient and reliable information about psychotropic medications; 3) the ease with which psychotropic medication prescriptions were obtained and the lack of alternatives to medication; 4) inconsistencies in medication compliance; 5) complicating factors related to out-of-home placement; and 6) the belief that professionals did not take adequate time to listen to and evaluate the youth for the appropriateness of medication.

Research conducted by Community Care Behavioral Health (CCBH), the behavioral health managed care organization for Medicaid recipients in Allegheny County, and DHS's Office of Data Analysis, Research and Evaluation (DARE) provided quantitative results that support these concerns. The research focused on psychotropic drug use among the 1,860 Allegheny County youth ages 17 and under who were Medicaid-enrolled and in out-of-home placement in the child

welfare or juvenile justice system for at least 30 days in 2010. This population was compared to Medicaid-enrolled youth of the same age who were not in out-of-home placement during that time. The evaluation shows that foster-care youth were approximately two and a half times more likely to be taking at least one psychotropic medication than their peers who were not in placement (27 percent compared to 11 percent). In addition, 11 percent of the 496 foster-care youth taking at least one psychotropic medication were actually taking three or more medications, nearly three times that of the comparison group.

In addition to providing a summary of the focus group process and the outcomes and quantitative data about the frequency with which psychotropic medications were prescribed, the report provides follow-up recommendations that include further research by CCBH/DHS, formation of a local workgroup to address the issue of psychotropic medication use by youth in placement, and development of educational materials for parents and caregivers to provide them with the information they need to advocate for the best interest of the children and youth in their care.

BACKGROUND

The use of psychotropic medications to treat youth in foster-care has received a great deal of attention on the national and local levels. Several studies found that the prescription for and use of psychotropic medications by children in foster care are significantly higher than youth of the same age who are not in out-of-home placement (dosReis, S., et al., 211; Leslie, L., et al., 2010; Longhofer, J., Floersch, J. and Okpych, N., 2011; and Zito, J., et al., 2008). Prescription guidelines and recommendations for ways to address this issue have appeared in the literature and been published by a variety of organizations (Walkup, J., et al., 2009; Texas, 2010; and Department, 2011).[1] A local analysis by Community Care Behavioral Health (CCBH) and the Department of Human Services (DHS) provides further evidence that psychotropic medications are prescribed more frequently for youth in out-of-home placements. This analysis compared medicaid-enrolled youth in Allegheny County who were age 17 or younger and had been in an out-of-home placement for 30 days during 2010, with their peers who had not been placed in a foster care setting during that time.

[1] Additional information resources about the use of psychotropic medication for children in out-of-home placement can be found in the Bibliography on page 10.

Pennsylvania is among those states seeking to address this issue, and in August of 2011, the Administrative Office of Pennsylvania Courts (AOPC) formed a Psychotropic Medication Workgroup and charged it with simplifying and improving the system of behavioral intervention for children and youth in the child welfare system. Because of the high level of interest in this issue at the national level, and as a result of concern at the local level about the overuse of psychotropic medications with this population, the first priority identified by this group was to investigate and address the high rate at which psychotropic medications are prescribed for youth in foster care. To achieve this mission, the workgroup first held focus groups with youth and caregivers throughout the state to learn more about their experiences using psychotropic

medications while in a child welfare out-of-home placement. In December 2011, DHS and the Allegheny County Family Law Center jointly undertook the planning and implementation of focus groups about the use of psychotropic medications by youth in child welfare out-of-home placement settings. Three focus groups were held in Allegheny County in January 2012.

The focus groups were held at the Human Services Building in downtown Pittsburgh in the early evening. Recruitment techniques included a flyer and personal contacts with providers to request that they make individual calls requesting participation by eligible[2] youth and caregivers. Each participant completed a consent form. Participants received a meal, and child care was provided during the focus groups; gift cards were distributed to compensate participants for their time. Due to the large number of responses for the caregiver focus group, an additional session was scheduled.

[2] Those eligible for the caregiver focus group included caregivers of youth who had experienced a child welfare out-of-home placement at some point in their life and who currently took, or had a history of taking, one or more psychotropic medications. Youth participants had to have experienced a child welfare out-of-home placement at some time in their lifetime, be at least 18 years of age and be a current or past user of psychotropic medications.

FOCUS GROUPS

Twenty-four individuals participated in the three DHS focus groups, 16 caregivers participated in the two caregiver focus groups, and eight youth participated in the youth focus group.[3] (For details, please see Survey Results in Appendix B on page 15).

[3] The demographic composition of the caregiver and youth focus groups does not represent the composition of either population.

Caregivers

All but one (94 percent) of the caregivers were female. Caregiver ages ranged from 26 to 66+, and 80 percent (13) were African American. Most of the caregivers (10, or 63 percent) were biological parents of children who took psychotropic medications and were placed out of home. Only one person identified as a foster parent; three were adoptive parents, and two identified as a step-parent and a grandparent.

Youth

The youth were divided equally between male and female. Five (63 percent) were 18 through 20 years of age; three (38 percent) were 21 through 25 years of age. All were African American, had experienced an out-of-home placement and took psychotropic medications during that placement.

Focus Group Findings

Beginning with a questionnaire developed by the PA Psychotropic Medication Workgroup, questions were reviewed and customized for caregiver and youth focus groups (see Appendix A on page 11). Participants were asked to describe their experiences with medication, to identify what worked and didn't work in that process, and to suggest ways in which systems can improve the way psychotropic medications are prescribed. In addition, a survey was distributed at the end of the focus groups to gather information about psychotropic medication use among focus group participants, their experiences with medical professionals and their perceptions about the benefits of the medication (see Appendix B on page 15).

There was a great deal of consistency in the themes discussed in both the caregiver and the youth focus groups, although each population brought a slightly different perspective to the issues. Six cross-cutting themes were identified and are summarized below: 1) reactions to medication recommendation/perceived stigma; 2) absence of adequate and/or reliable information about psychotropic medications; 3) the ease with which psychotropic medications were prescribed and the lack of alternatives to medication; 4) inconsistencies in medication compliance; 5) complicating factors related to out-of-home placement; and 6) the belief that professionals did not take adequate time to listen to and evaluate the youth for the appropriateness of medication. Detailed responses can be found in Appendix C on page 19.

1. **Reactions to Medication Recommendation/Perceived Stigma:** Initial reactions to the news that psychotropic medication was being recommended varied among caregiver and youth participants. Some caregivers were relieved while others were worried about medicating their child. Most youth were too young to remember their initial reaction; however, many noted that they were worried about how others would perceive them if it was known that they were taking medication. This concern was raised both by the youth and by the caregivers, who reported on the stigma their child felt as a result of taking medication.
2. **Absence of Adequate/Reliable Information about Psychotropic Medications:** For both caregivers and youth, access to reliable and understandable information about the psychotropic medications being prescribed played an important role in the attitudes they had about medication and the options they pursued over time.

   For caregivers, much of this was shaped by the relationship forged with their child's doctor or psychiatrist. Some caregivers said that their doctor or psychiatrist took the time to discuss medication pros and cons with them, including side effects, dosage and long-term effects. Others, however, had the opposite experience. Many were unsure of the side effects and long-term effects their child would experience as a result of the medication. Some also said they were worried that the new medication would interact with other medications their child was taking. Finally, some caregivers discussed the challenge of being caught between a physical health doctor and a psychiatrist who did not agree on the issue of psychotropic medications for the child. The conflicting information they received compounded their fear and worry about consenting to the prescription.

   As the youth described their experiences with taking psychotropic medication(s), it became clear that the majority of them had little information about what they were taking. Some youth discussed how they learned that they had rights related to taking medication and then began to ask questions and get more information about what they were taking. Based on their experiences, especially with side effects, others came to their own conclusions about what the medications they were taking would or wouldn't do for them.

   As a result of not having the information they needed, most of the caregivers discussed the process they went through to educate themselves about their child's diagnosis and the medication(s) he/she was prescribed. In addition to doing research on the Internet, several

talked about attending conferences to increase their knowledge. They used this information to empower themselves when having conversations with doctors/psychologists about their child's diagnosis and medication(s).

3. **The Ease with which Psychotropic Medications were Prescribed and the Lack of Alternatives to Medication:** Both caregivers and youth discussed how readily doctors and psychiatrists prescribed psychotropic medications. Youth in particular spent a lot of time discussing how easy it was to get a prescription when they were in an out-of-home placement. Many described seeing a doctor/psychiatrist for only a few minutes before getting a prescription. Caregivers and youth both discussed the lack of alternatives to medication and their desire that alternatives be tried first. One caregiver reported that she worked with the doctor to take her child off of all medications; the child was then enrolled in play therapy, which was quite effective. The majority of youth wanted to try alternative interventions (e.g., reading, physical activity, mentoring) before medication. Many youth noted that they were not given the opportunity to exercise their right to refuse medication.

4. **Inconsistencies in Medication Compliance:** Both caregiver and youth focus group participants reported that youth sometimes failed to take medications as prescribed, sometimes due to side effects and sometimes to exercise their right to stop using medication. For caregivers, this became a power and control issue.

   In Pennsylvania, when a child turns 14, he/she has the right to refuse treatment and/or medication. Many of the caregivers described how their children responded to this by refusing their medication, especially when the medication started to work and they felt better; unfortunately, stopping the medication often resulted in a re-emergence of the behaviors that necessitated the medication to begin with. Hence, families felt trapped in a cycle that they could not influence.

   The majority of youth in the focus group did not take their medications as prescribed, either by their own choice, such as when they ran away from their out-of-home placement, or by manipulating the system (e.g., putting the pill under their tongue and then spitting it out). Some stopped taking their medication due to its side effects.

5. **Complicating Factors Related to Out-of-Home Placement:** Both caregivers and youth had difficulty separating experiences related to medication from the experience of out-of-home placement in general. It was clear that medication was just one of the complications that youth experience when placed out of home and/or moved between various out-of-home settings.

   Some caregivers discussed how out-of-home placement complicated their ability to determine whether medication was the right choice for the youth involved. One caregiver reported that her child was prescribed medication after being removed to a foster home, thus putting medication decisions in the hands of someone who might not give the appropriate level of attention to the matter. Another caregiver described the challenge of caring for a foster child without knowing the medical history of the biological family, making the decision to place the child on psychotropic medications even more difficult.

Several youth acknowledged that being removed from their home was probably the right thing and that it may have even saved their lives. Nevertheless, the majority also discussed their sadness about being placed with people who (in their perception) cared for them only because it was their job and not a reflection of genuine love and caring. Further complicating the situation, and compounding the problem of a lack of consistency of care, was the fact that the majority of youth in the focus groups had experienced multiple placements, sometimes within the same year. These multiple placements had the potential to negatively impact the youth's education and ability to develop independent living skills.

6. **The Belief that Professionals Do Not Take Adequate Time to Listen to and Evaluate the Youth for the Appropriateness of Medication:** Both groups expressed their frustration and desire to be heard by those who were providing care. Many caregivers discussed their attempts to describe for their child's doctor or psychiatrist what was happening at home so that this information could be considered when ordering medication or making dosage changes; the caregivers often felt that their voices fell on deaf ears. Youth described feelings of isolation. The majority felt that no one listened to them or took the time to understand their experiences; they also did not feel that their individual preferences were taken into consideration. These feelings contributed to rebellion on the part of the youth. Further, these experiences shaped their view of what to expect in the future.

QUANTITATIVE ANALYSIS

The analysis conducted by CCBH and DHS provided quantitative support to these perceptions on the part of the focus group participants. The analysis looked at Medicaid-enrolled youth ages 17 and younger who had at least 30 days of out-of-home placement (either in the child welfare or the juvenile justice system) and at least 80 percent Medicaid eligibility during 2010. Using these criteria, 1,860 Allegheny County youth met the criteria. By comparison, there were 69,103 Allegheny County youth ages 17 and younger who were enrolled in Medicaid but not in out-of-home placement 80 percent of the time. Twenty-seven percent of the foster-care youth (496) were taking at least one psychotropic medication as compared to 11 percent of non–foster-care youth; there were significant differences by age and race (see Appendix D on page 24). In addition, 11 percent of the 496 foster-care youth taking at least one psychotropic medication were taking three or more psychotropic medications, which is almost three times the rate of non–foster-care youth (see Appendix D on page 25). **Table 1**, below, compares psychotropic medication use by youth in Allegheny County and five states in which this issue was studied using comparable criteria and medication classes.

TABLE 1: **Psychotropic Medication Use by Foster-Care and Non–Foster-Care Youth, Allegheny County and Selected States, 2010**

	YOUTH IN FOSTER CARE	YOUTH NOT IN FOSTER CARE
Florida	22%	8%
Massachusetts	39%	10%
Michigan	21%	8%
Oregon	20%	5%
Texas	32%	7%
Allegheny County	27%	11%

SOURCE: GAO

CONCLUSIONS AND RECOMMENDATIONS

Conclusions

Both focus group populations identified similar themes related to psychotropic medication use for youth in out-of-home placement. The data analysis conducted by CCBH appears to corroborate the belief, expressed in the focus groups, that psychotropic medication is prescribed more frequently for children in out-of-home placement; 27 percent of Allegheny County youth in out-of-home placement as compared to 11 percent of youth who have not been placed, for a ratio greater than two to one.

Recommendations

CCBH

- CCBH is conducting research in other Community Care counties for additional comparison; data is being compiled.
- CCBH will further analyze the high rate of psychotropic medication use in placed and non-placed youth.
- CCBH will follow up with prescribers to educate them about the higher-than-average prescribing rates for those in out-of-home placement.

DHS

- DHS will form a local workgroup to address the topic of psychotropic medication use by youth in placement.
- DHS will prepare educational materials for parents and caregivers, to provide them with information about: 1) the benefits and risks of psychotropic medication; 2) alternative treatments; and 3) the skills necessary to advocate for what is in the best interest of their children.

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APPENDIX A: CAREGIVER AND YOUTH FOCUS GROUP QUESTIONS

Caregiver Questions

Opening Question

1. Let's go around the room to get to know each other a little better. Please tell us your name and one thing about your child/foster child that you are proud of.

Introductory Questions

2. Thinking back to when someone first told you that your child/foster child needed a psychotropic medication, what was your reaction? Probes:
   a. For example, did you feel a certain way or have an opinion about your child/foster child taking medication?

3. Who first explained the need for medication to you, and what did they tell you about it? Probes:
   a. For example, did they talk about ways the medication would affect your child/foster child or why he/she should take it?

Transition Question

4. Was there a clear connection for you between what was going on in your child's/foster child's life at the time he/she was prescribed medication and how the medication would help during that time? Why or why not? Probes:
   a. Who were the people helping you understand the connection between your child's/foster child's life situation and the medication?
   b. Can you describe what was going on in your child's/foster child's life a bit further?

Key Questions

5. How empowered did you feel during the process of prescribing your child/foster child with a psychotropic medication to say whether you agreed with the treatment or not? Probes:
   a. Why did you feel empowered / un-empowered?

6. After your child/foster child started taking a prescribed psychotropic medication, what was his/her experience with it? Probes:
   a. For example, what was particularly helpful or unhelpful about it for your child/foster child?

Appendix A: Caregiver and Youth Focus Group Questions
(continued)

7. What did you do if your child/foster child experienced side effects or problems as a result of the medication? Probes:
   a. Do you think the problems experienced with the medication were resolved to your satisfaction? Why or why not?

8. A variety of experiences have been discussed by the group up to this point. Thinking overall about the process and experiences you went through with psychotropic medication in your life, what worked and what would you change? Probes:
   a. For example, what would you personally have done the same way or differently?
   b. For example, what could the systems you were involved with have done differently, and what would you keep the same?

Closing Questions

9. If you could give advice to other caregivers who went through what you did, what would that advice be? Probes:
   a. For example, what would you tell them to do that you did or did not do?

10. If you could give advice to professionals who work with young adults and families who went through what you did, what would that advice be? Probes:
    a. For example, what would you tell them to do that you did or did not do?

11. When we started the focus group, we talked about wanting to learn about your experiences with having a child/foster child who took psychotropic medications and what is and is not working in our service systems for youth. Is there anything we missed? Is there anything that you came here wanting to say that you didn't get a chance to say?

Youth Questions

Opening Question

1. Let's go around the room to get to know each other a little better. Please tell us your name and one accomplishment in your life that you are proud of [or could word to ask for: one thing you enjoy doing — it could be a hobby, interest, etc.].

Introductory Questions

2. Thinking back to when someone first told you that you needed a psychotropic medication, what was your reaction? Probes:
   a. For example, did you feel a certain way or have an opinion about taking medication?

Appendix A: Caregiver and Youth Focus Group Questions
(continued)

3. Who first explained the need for medication to you, and what did they tell you about it? Probes:
    a. For example, did they talk about ways the medication would affect how you feel or why you should take it?

Transition Question

4. Was there a clear connection for you between what was going on in your life at the time you were prescribed medication and how the medication would help during that time? Why or why not? Probes:
    a. Who were the people helping you understand the connection between your life situation and the medication?
    b. Can you describe what was going on in your life a bit further?

Key Questions

5. After you started taking a prescribed psychotropic medication, what was your experience with it? Probes:
    a. For example, what was particularly helpful or unhelpful about it?

6. What did you do if you experienced side effects or problems as a result of the medication? Probes:
    a. Do you think the problems you experienced with the medication were resolved to your satisfaction? Why or why not?

7. How empowered did you feel during the process of being prescribed a medication to say whether you should take it or not and/or to say when you wanted to discontinue use of it? Probes:
    a. Why did you feel empowered / un-empowered?
    b. Who helped you to feel empowered or who hindered your ability to feel empowered in that way?

8. A variety of experiences have been discussed by the group up to this point. Thinking overall about the process and experiences you went through with psychotropic medication in your life, what worked, and what would you change? Probes:
    a. For example, what would you personally have done the same way or differently?
    b. For example, what could the systems you were involved with have done differently, and what would you keep the same?

Appendix A: Caregiver and Youth Focus Group Questions
(continued)

Closing Questions

9. If you could give advice to other young adults who went through what you did, what would that advice be? Probes:
    a. For example, what would you tell them to do that you did or did not do?

10. If you could give advice to professionals who work with young adults who went through what you did, what would that advice be? Probes:
    a. For example, what would you tell them to do that you did or not do?

When we started the focus group, we talked about wanting to learn about your experiences with psychotropic medications and what is and is not working in our service systems for youth. Is there anything we missed? Is there anything that you came here wanting to say that you didn't get a chance to say?

APPENDIX B: CAREGIVER AND YOUTH SURVEY DEMOGRAPHICS AND RESULTS

TABLE 2: Caregiver and Youth Survey Demographics and Results

	CAREGIVER RESPONDENTS N=16		YOUTH RESPONDENTS N=8		COMBINED TOTAL N=24	
SEX						
Male	1	6%	4	50%	5	21%
Female	15	94%	4	50%	19	79%
AGE						
18–20	0	-	5	63%	5	21%
21–25	0	-	3	38%	3	13%
26–45	6	38%	-	-	6	25%
46–55	5	31%	-	-	5	21%
56–65	4	25%	-	-	4	17%
66+	1	6%	-	-	1	4%
RACE						
African American	13	81%	8	100%	21	88%
White	3	19%	0	-	3	12%
RELATIONSHIP TO CHILD						
Biological Parent	10	63%	-	-	10	63%
Foster Parent	1	6%	-	-	1	6%
Adoptive Parent	3	19%	-	-	3	19%
Other	2	13%	-	-	2	13%
OVER YOUR LIFETIME, WHAT TYPES OF PSYCHOTROPIC MEDICATIONS HAVE YOU TAKEN? **NOTE: RESPONDENTS COULD PROVIDE MORE THAN ONE ANSWER*						
Anti-Psychotics	-	-	4	50%	4	50%
Anti-Depressants	-	-	3	38%	3	38%
Mood Stabilizers	-	-	2	25%	2	25%
Anti-Anxiety	-	-	2	25%	2	25%
Beta-Blockers	-	-	0	0%	0	0%
Stimulants	-	-	3	38%	3	38%
Other	-	-	2	25%	2	25%
HOW MANY DIFFERENT PSYCHOTROPIC MEDICATIONS DID YOU TAKE AT THE SAME TIME?						
One	-	-	0	0%	0	0%
Two	-	-	5	63%	5	63%
Three	-	-	0	0%	0	0%
Four	-	-	1	13%	1	13%
Five or More	-	-	1	13%	1	13%
Don't Know	-	-	1	13%	1	13%

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Appendix B: Caregiver and Youth Survey Demographics and Results

(continued)

	CAREGIVER RESPONDENTS N=16		YOUTH RESPONDENTS N=8		COMBINED TOTAL N=24	
WHAT WAS THE LONGEST PERIOD OF TIME THAT YOU TOOK ONE OR MORE PSYCHOTROPIC MEDICATIONS?						
< One Month	-	-	1	13%	1	13%
1–3 Months	-	-	1	13%	1	13%
3–6 Months	-	-	0	0%	0	0%
6 Months – 1 Year	-	-	1	13%	1	13%
1–2 Years	-	-	1	13%	1	13%
2 Years +	-	-	3	38%	3	38%
Don't Know	-	-	1	13%	1	13%
WERE YOU EVER ASKED TO PROVIDE INFORMED CONSENT FOR YOUR CHILD/FOSTER CHILD TO TAKE PSYCHOTROPIC MEDICATION?						
Yes	12	75%	-	-	12	75%
No	3	19%	-	-	3	19%
Don't Know	1	1%	-	-	1	1%
DID YOU UNDERSTAND WHY PSYCHOTROPIC MEDICATION WAS PRESCRIBED?						
Yes	8	50%	3	38%	11	46%
Somewhat	6	38%	-	-	6	25%
No	2	13%	4	50%	6	25%
Don't Know	-	-	1	12%	1	4%
IN GENERAL, HOW WELL DID YOU UNDERSTAND HOW THE PSYCHOTROPIC MEDICATION NEEDED TO BE TAKEN AS PRESCRIBED?						
Very Well	6	38%	1	13%	7	29%
Somewhat	3	19%	2	25%	5	21%
Not at All	0	0%	4	50%	4	17%
No Answer	7	44%	1	13%	8	33%
ON AVERAGE, HOW OFTEN DID YOU SEE THE DOCTOR THAT PRESCRIBED PSYCHOTROPIC MEDICATION?						
Weekly	-	-	2	25%	2	25%
Monthly	-	-	3	38%	3	38%
Bi-Monthly	-	-	1	13%	1	13%
Every 3 Months	-	-	0	0%	0	0%
Every 6 Months	-	-	1	13%	1	13%
Annually	-	-	0	0%	0	0%
Never	-	-	0	0%	0	0%
No Answer	-	-	1	13%	1	13%
WERE YOU AWARE OF THE SIDE EFFECTS PSYCHOTROPIC MEDICATIONS MIGHT CAUSE?						
Yes	6	38%	1	13%	7	29%
Somewhat	5	31%	4	50%	9	38%
No	5	31%	2	24%	7	29%
No Answer	-	-	1	13%	1	4%

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Appendix B: Caregiver and Youth Survey Demographics and Results

(continued)

	Caregiver Respondents N=16		Youth Respondents N=8		Combined Total N=24	
DID YOU / YOUR CHILD OR FOSTER CHILD EXPERIENCE NEGATIVE SIDE EFFECTS FROM PSYCHOTROPIC MEDICATION?						
Yes	8	50%	6	75%	14	58%
No	8	50%	1	13%	9	38%
No Answer	-	-	1	13%	1	4%
IF YES, DID YOU REPORT THE SIDE EFFECTS TO SOMEONE WHO COULD HELP?						
Yes	6	75%	5	62%	11	79%
No	2	25%	1	13%	3	21%
IF YES, DID YOU FEEL THAT YOUR REPORTING OF SIDE EFFECTS WAS TAKEN SERIOUSLY?						
Yes	2	33%	0	0%	2	18%
No	4	67%	5	100%	9	82%
IN GENERAL, HOW HELPFUL HAS PSYCHOTROPIC MEDICATION BEEN FOR YOU / YOUR CHILD OR FOSTER CHILD?						
Very Helpful	5	31%	0	0%	5	20%
Somewhat Helpful	8	50%	3	38%	11	46%
Not Helpful	1	6%	3	38%	4	17%
No Answer	2	13%	2	25%	4	17%
WERE YOU / WAS YOUR CHILD OR FOSTER CHILD EVER OFFERED THERAPY, COUNSELING OR ANOTHER SERVICE ALONG WITH PSYCHOTROPIC MEDICATION?						
Yes	12	75%	3	38%	15	63%
No	2	13%	2	25%	4	17%
Don't Know	2	13%	2	25%	4	17%
No Answer	-	-	1	13%	1	4%
WERE YOU / WAS YOUR CHILD OR FOSTER CHILD EVER OFFERED THERAPY, COUNSELING OR ANOTHER SERVICE INSTEAD OF PSYCHOTROPIC MEDICATION?						
Yes	8	50%	3	38%	11	46%
No	7	44%	3	38%	10	42%
Don't Know	1	6%	1	13%	2	8%
No Answer	-	-	1	13%	1	4%
DID YOU / DO YOU FEEL LIKE YOU HAVE A CHOICE TO CONTINUE OR DISCONTINUE YOUR / YOUR CHILD'S OR FOSTER CHILD'S PSYCHOTROPIC MEDICATION USE?						
Yes	8	50%	2	25%	10	42%
No	4	25%	5	63%	9	38%
Unsure	2	13%	1	13%	3	13%
Not Applicable	2	13%	-	-	2	8%
HAVE YOU EVER DECIDED TO REFUSE OR DISCONTINUE USE OF YOUR / YOUR CHILD'S OR FOSTER CHILD'S PSYCHOTROPIC MEDICATION?						
Yes	7	44%	6	75%	13	54%
No	9	56%	1	13%	10	42%
No Answer	-	-	1	13%	1	4%

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Appendix B: Caregiver and Youth Survey Demographics and Results

(continued)

	CAREGIVER RESPONDENTS N=16		YOUTH RESPONDENTS N=8		COMBINED TOTAL N=24	
IF YES, WAS YOUR DECISION WELL RECEIVED BY THE DOCTOR OR PSYCHIATRIST WHO PRESCRIBED THE MEDICATION?						
Yes	3	43%	2	25%	5	38%
No	4	57%	4	50%	8	62%
IF YOU ARE A FOSTER PARENT, DID YOU RECEIVE TRAINING REGARDING PSYCHOTROPIC MEDICATION?						
Yes	2	12%	-	-	2	12%
No	3	19%	-	-	3	19%
Not Applicable	4	25%	-	-	4	25%
No Answer	7	44%	-	-	7	44%
IF YES, HOW SATISFIED WERE YOU WITH THE INFORMATION THAT YOU RECEIVED IN THE PSYCHOTROPIC MEDICATION TRAINING?						
Very Satisfied	0	0%	-	-	0	0%
Satisfied	2	100%	-	-	2	100%
Unsatisfied	0	0%	-	-	0	0%
Very Unsatisfied	0	0%	-	-	0	0%

APPENDIX C: CAREGIVER AND YOUTH RESPONSES

1. Reactions to Medication Recommendation/Perceived Stigma

Caregiver Initial Reactions

- I was almost relieved… his behavior escalated. Now he is on medicine that has enabled a 180-degree turnaround, and he is great!
- I was in favor [of medication] because my child was out of control and needed help.
- I was very skeptical at first. I weighed the pros and cons and talked to friends. The doctors helped me to choose [medication].
- I was against [medication] because I didn't understand. I felt my child may become addicted. The doctor was quick to prescribe [medications], and I did not know what they were for.

Youth Initial Reactions

- I wasn't old enough to need meds. I was 5.
- My mom told me I needed to take it [medication] to be more settled in school.
- I'm not crazy. I didn't want anybody calling my name to come get meds. Then everyone looks at you like you're the crazy one.
- They lie to you. They tell you it'll make you be how they want you to be.
- Even my neighbors would pick on my son. There was no compassion. There is illness everywhere. None of us can do it alone. We must do it as a team.
- There were self-esteem issues when my child gained weight from the medication.
- The school would make an announcement around the other children for my child to go to the nurse's office. He was embarrassed, and the other kids would tease him.

2. Absence of Adequate/Reliable Information about Psychotropic Medications

Caregiver Comments

- The doctor at Western Psych sat down and explained everything very carefully. He weighed my son to be sure to get the right dose.
- They [doctors/psychiatrist] showed me a picture of the brain and the energy that goes to it and how [my son] is hindered. The doctor described the meds and explained the possible reactions and next steps.
- Doctors need to talk in laymen's terms.
- They [doctors] should do a better job explaining side effects.
- The physical health doctor and mental health [psychiatrist] need to communicate to each other.

Appendix C: Caregiver and Youth Responses
(continued)

- It was helpful for me to go to conferences and learn how to advocate for my child.
- My son was diagnosed young, but they never explained much. I had to learn on my own.
- Not all kids need medication. Parents need to educate themselves more. Ask the doctor questions about meds. Be a proactive parent.

Youth Comments

- Nobody told me anything. The lady just gave it [medication] to me.
- I had no idea what I was taking until I was old enough to start asking questions. When I was 14, a staff worker first told me I had rights, and that gave me the chance to ask about it.
- The majority of meds is a scam. They are placebos. All based on group statistics, not the individual situation.
- I don't think meds work. I did the same stuff when I was on and when I was off the meds.

3. The Ease with which Psychotropic Medications were Prescribed and the Lack of Alternatives to Medication

Caregiver Quotes

- The doctor did not acknowledge my concerns and was quick to give prescriptions.
- The dosage went up to 6–7 meds for one diagnosis. Would you give that to your family member?
- I did my own research and found alternatives [therapy] that were successful, so I felt empowered.
- My son had several diagnoses — ADHD, OCD and seizures. I was worried about the various meds interacting with each other. I did my own research to find a good fit.

Youth Quotes

- They are too quick to put kids on meds. Kids are going to act like kids — especially when they are taken away from their family… Of course a kid is going to act out or be depressed.
- You say you miss being at home and they put you on pills for depression. What kid isn't going to miss being at home? That's not depressed!
- A kid may be high on sugar — but they said he has ADHD and put him on meds. Do they know he just drank eight glasses of Kool-Aid?
- The doctors are too busy. All mental health evaluations are done in the same place. How can they diagnose you when they see you for five minutes?
- The only thing they offered me was meds — nothing else.
- They should offer other alternatives to meds — like football or exercise. They should prescribe a book — or anything the kid might like. Link up with Big Brothers/Big Sisters or a mentor. Someone who can pay attention to the kid.

Appendix C: Caregiver and Youth Responses
(continued)

- They say you have the right to refuse, but then they take everything away from you if you do. So it is not really a choice.
- You had no choice but to take [the meds]. If you don't take the meds, they take away your home visits and other privileges.
- Once they decide you need meds, it becomes part of your goal plan, so you have to take them.
- My foster mom said I couldn't live there unless I took meds.

4. Inconsistencies in Medication Compliance

Caregiver Comments

- A 14-year-old should not be given so much power [to refuse medication] at that age. What does he know?
- They give kids too much power. My 14-year-old "fired" his wraparound team... He fired his doctor too. He acts disrespectful, and he is given the power to do that.
- My kid will tell a doctor "I don't want my mother in here" or "Don't tell my mom anything." His privacy rights go too far. I am still his mother.
- My kids take their meds until they feel they are okay and then they stop, so it cycles. This needs to be in the hands of adults.
- My kid stopped taking his meds and ran away. I called the police, but they wouldn't do anything... But if he harmed someone, they'd hold me responsible.
- The ill have rights, but they should incorporate the parent's point of view.

Youth Comments

- I was only on the meds when I was in placement. When I'd run, I didn't take the meds. When I was back, I'd take them again.
- I went on the run. That's when I stopped taking meds. But each time I'd come back, I'd take them again and stop when I ran.
- I would put them under my tongue and then spit it out.
- I was out of the house [biological parents'] and upset at the world. I acted out and got aggressive and suicidal. I would put the pill under my tongue. My foster parents could tell when my meds were taken or not.
- I would be given high doses of the medications, and I would hide them.
- I felt good when I was on meds, but I gained 50 pounds. When I went off my meds, I smoked more weed.
- Those meds have side effects and make you crazy. I think all kids who were put on meds should get disability checks.

Appendix C: Caregiver and Youth Responses
(continued)

- I couldn't eat, I couldn't move. It was like I was in a full body straightjacket. Like a brainwash pill.
- My mother used to beat me. I would rather be beaten than take meds!

5. Complicating Factors Related to Out-of-Home Placement

Caregiver Experience

- When my child was diagnosed, I had CYF involvement. I needed to know where he was being placed and who was going to administer the meds. While my kids were out of my care, I worried about whether their caregivers were giving them proper care….
- I adopted a teenage child and did not know he had post-traumatic stress disorder. It would be helpful to have a history because DNA plays a role.

Youth Experience

- We get thrown on someone's overloaded caseload. They don't know anything about me. I don't know who they are or if they are qualified. There's no personal treatment based on the individual.
- My foster mom…only cared about the check she got. She never spent it on me.
- I was placed with girls ranging in age between nine and 17. They took us to Chuck E Cheese. That is not something for older girls. They try to find activities for everyone, but the age range is too big.
- They [foster parents] never took me to good stores. Payless for me and Foot Locker for their kids.
- They need more staff. More people to listen to you. I've been a ton of places. There's not enough staff who care about you. I've been in seven places and only had two staff people I liked. They don't take time to listen to you or help with the problem.
- I've been in 30 different beds. I never finished one school in the same year. So no one could ever really know me and what I was about or what I needed. No one ever diagnosed my learning disability.
- Every new placement, it was "Here's the refrigerator, here's your bed" — new rules. On the good side, I learned to adapt to anything!
- They move you around too much! There is no continuity.
- They need to teach kids life skills. They don't teach you anything. Not how to wash myself as a woman, not how to wash dishes or navigate a system.
- I was moved too many places. I couldn't do stuff like fractions. I ran from lots of placements. I was on the street. I learned how to do what I need to do; I can count money.

Appendix C: Caregiver and Youth Responses
(continued)

6. The Belief that Professionals Do Not Take Adequate Time to Listen to and Evaluate the Youth for the Appropriateness of Medication

Caregiver Perceptions

- The doctor did not acknowledge my concerns and was quick to give prescriptions.
- What they told me would happen with my kid did not happen despite all of the different dosages. My observations fell on deaf ears. They wanted to see more changes than were happening and would not value my observations.
- The parent is the expert on their child!
- I want doctors to listen to everything. Not just the key words — the whole story.

Youth Perspectives

- You put nine or 10 males, all in puberty, taken from their family, together in a home. Of course they will get triggered and act out. What do they expect?
- Even with all the security, I know how to work the system. I know how to get a bed and a meal.
- They institutionalize you so much that you're already prepared for jail. You're so used to having no freedom, no decisions to make, no choices.
- Fake it til you make it. It taught me how to manipulate a system.
- You can trade your sleeping pills for lots of stuff in placement. Even after it has been in your mouth and you spit it out.
- The caseworker always believes the parent over you. Like you got the issue — not them.
- Most kids who age out of CYF are homeless or in jail or dead.
- They teach you to pop pills. To experiment. They say "Try this." No wonder we all try so many drugs!
- You get accused of popping pills and they say you're an addict. Yeah, but you prescribed it! They give us weapons without even knowing it.

APPENDIX D: PSYCHOTROPIC MEDICATION USE IN FOSTER-CARE CHILDREN AND NON–FOSTER-CARE CHILDREN

TABLE 3: Psychotropic Medication Use in Foster-Care Children and Non–Foster-Care Children (Ages 0 through 17)

	PERCENT OF FOSTER-CARE CHILDREN ON PSYCHOTROPIC MEDICATION BASED ON TOTAL NUMBER OF FOSTER-CARE CHILDREN (N=1860)	DISTRIBUTION OF FOSTER-CARE CHILDREN ON A PSYCHOTROPIC MEDICATION (N=496)	PERCENT OF NON–FOSTER-CARE CHILDREN ON PSYCHOTROPIC MEDICATION BASED ON TOTAL NUMBER OF NON-FOSTER CARE CHILDREN (N=69103)	DISTRIBUTION OF NON–FOSTER-CARE CHILDREN ON PSYCHOTROPIC MEDICATION (N=7670)	RATIO OF FOSTER-CARE TO NON–FOSTER-CARE CHILDREN ON PSYCHOTROPIC MEDICATION
AGE					
Under 1	(2) 0.1%	0%	(32) 0%	0.4%	2.3
1 – 5	(22) 1%	4%	(659) 1%	9%	1.2
6 – 12	(129) 7%	26%	(4057) 6%	53%	1.2
12 – 17	(343) 18%	63%	(2922) 4%	38%	4.4
Total	**(496) 27%**		**(7670) 11%**		**2.4**
RACE					
African American	(290) 16%	59%	(2394) 4%	31%	4.5
Asian	(0) 0%	0%	(27) 0%	0%	0.0
Native American	(0) 0%	0%	(9) 0%	0%	0.0
Other	(19) 1%	0%	(377) 1%	5%	1.9
White	(187) 10%	38%	(4863) 7%	63%	1.4
Total	**(496) 27%**		**(7670) 11%**		**2.4**
PLACEMENT (ALLEGHENY COUNTY FOSTER CARE DATA ONLY)					
CYF	(399) 22%	80%			
JPO	(97) 5%	20%			

Appendix D: Psychotropic Medication Use in Foster-Care Children and Non–Foster-Care Children

(continued)

TABLE 4: **Psychotropic Polypharmacy for Foster-Care and Non–Foster-Care Children (Ages 0 through 17)**

	PERCENT OF FOSTER-CARE CHILDREN ON 3 OR MORE PSYCHOTROPIC MEDICATIONS BASED ON FOSTER-CARE CHILDREN ON AT LEAST 1 PSYCHOTROPIC MEDICATION (N=496)	DISTRIBUTION OF FOSTER-CARE CHILDREN ON 3 OR MORE PSYCHOTROPIC MEDICATIONS (N=58)	PERCENT OF NON–FOSTER-CARE CHILDREN ON 3 OR MORE PSYCHOTROPIC MEDICATIONS BASED ON NON–FOSTER-CARE CHILDREN ON AT LEAST 1 PSYCHOTROPIC MEDICATION (N=7670)	DISTRIBUTION OF NON–FOSTER-CARE CHILDREN ON 3 OR MORE PSYCHOTROPIC MEDICATIONS (N=322)	RATIO OF FOSTER-CARE TO NON–FOSTER-CARE CHILDREN ON 3 OR MORE PSYCHOTROPIC MEDICATIONS
AGE					
Under 1	(0) 0.0%	0%	(0) 0%	0%	0.0
1 – 5	(0) 0%	0%	(6) 0.1%	2%	0.0
6 – 12	(12) 2%	21%	(141) 2%	44%	1.3
12 – 17	(46) 9%	79%	(175) 2%	54%	4.0
Total	**(58) 12%**		**(322) 4%**		**2.8**
RACE					
African American	(23) 5%	40%	(51) 1%	16%	6.9
Asian	(0) 0%	0%	(0) 0%	0%	0.0
Native American	(0) 0%	0%	(1) 0%	0%	0.0
Other	(4) 1%	7%	(18) 0%	6%	4.0
White	(31) 6%	53%	(252) 3%	78%	1.9
Total	**(58) 12%**		**(322) 4%**		**2.8**
PLACEMENT (ALLEGHENY COUNTY FOSTER CARE DATA ONLY)					
CYF	(50) 10%	86%			
JPO	(8) 2%	14%			