State of Florida

Florida Statewide Advocacy Council

Red Item Report

Psychotropic Drug Use in Foster Care

July 2003

Jeb Bush, Governor

Betty Busbee, Chairperson

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State of Florida

Florida Statewide Advocacy Council

"Protecting and advocating for a better quality of life for Floridians with unique needs".

Introduction

This Red Item Report is issued by the Florida Statewide Advocacy Council ("SAC") to the Governor, Inspector General of the State of Florida, Director of the Florida Office of Drug Control, the Secretary of the Agency for Health Care Administration, the Secretary of the Department of Children and Family Services, the Secretary of the Department of Health, the Secretary of the Department of Juvenile Justice, the Secretary of the Department of Education, the Attorney General, the Florida Legislature, the Surgeon General of the United States, the Administrators for the United States Department of Health and Human Services Administration for Substance Abuse, Mental Health Services, Administration for Children and Families, and the Centers for Medicaid and Medicare Services, the United States Department of Health and Human Services Office of the Inspector General and the Public.

Under the authority of Section 402.164, et. seq., Florida Statutes, we protect and advocate for a better quality of life for Floridians with unique needs who are clients of state services as defined in Section 402.164(2)(a), Florida Statutes by monitoring and investigating state agencies, programs and service providers and individuals which monitoring and investigation shall safeguard and protect the consumer of state services against conditions or threats of a violation of client rights, health, safety or welfare. By conducting independent and objective monitoring and investigations, and through the determination of whether the presence of conditions or individuals that constitute a threat to the rights, health, safety and welfare of persons who receive services from the State of Florida, we provide timely, useful, and reliable information and advice to the Governor, state agencies heads or other decision-makers, the Florida Legislature and the Public.

SAC conducts and undertakes comprehensive monitoring of existing programs and services and new and revised programs of the state agencies that provide client services to determine how the rights of the clients are affected. SAC monitoring also encompasses announced as well as unannounced monitoring of facilities that are operated, funded or contracted by a state agency. SAC also provides overall leadership and direction to the Florida Local Advocacy Councils (LAC) in carrying out the local

program, services and facilities monitoring responsibilities mandated by the Florida Legislature relating to safeguarding the health, safety and welfare of consumers of services provided by state agencies.

From time to time in a Red Item Report we will request corrective action planning and make recommendations. Recommendations can be implemented by administrative action, while some may call for a change in legislation. Although these recommendations generally have a monetary impact when implemented, the state agencies may achieve some programmatic savings. SAC recommendations for proposed legislation are not removed until the law has been enacted – not just proposed. For administrative issues, recommendations are not removed until the action has been substantially completed.

The Red Item Report supplements other SAC reports. Section 402.165(7)(e), Florida Statutes requires an annual report to the Legislature and the Governor. In compliance with the SAC statute, significant recommendations are highlighted in the annual report. Because of the abbreviated nature of that report and the potentially significant impact of SAC recommendations, we prepare the Red Item Report to elaborate further on our most significant monetary issues that impact the health, safety, welfare and rights of our Clients. Through the Red Item Report, state agency officials, and the Governor and Legislature have in one document significant program and service improvement recommendations as to issues that affect the constitutional and human rights of the beneficiaries of our State's health and human services.

For the purposes of this report, our Clients under Section 402.164(2)(a), include any child or youth as defined in s. 39.01, any child as defined in s. 827.01, any Medicaid recipient or recipient as defined in s. 409.901, any child receiving childcare as defined in s. 402.302 as each definition applies within its respective chapter.

In our General Work Plan FY 2003, we indicated that in FY 2001, SAC initially launched an investigation into the utilization of psychotropic drugs in children in foster care. Based on data reviewed in FY 2002, the Psychotropic Drug Investigation Team, as appointed by SAC, concentrated its efforts in the following areas in FY 2003: Children on Psychotropic Drugs.

We stated we would investigate and evaluate the extent of the utilization of psychotropic drugs in children that receive services and we would determine whether there was valid consent to administer psychotropic drugs to our clients.

Executive Summary

There has been a considerable increase in the prescription of psychotropic drugs in children and adolescents in the United States over the last decade. This utilization in Florida was brought to the attention of the Statewide Advocacy Council in 2001, with reports of widespread use occurring in children in foster care under the supervision of the

Department of Children and Families in South Florida. When an internal investigation by the department was conducted, it concluded that the use of psychotropic drugs in children in their care was not a problem. However, information received from the Agency for Health Care Administration (AHCA) revealed that more than 9,500 children in Florida on Medicaid had been treated with psychotropic drugs in the year 2000. As a result, SAC began to monitor the use of these drugs in foster children over the state. The use of psychotropic drugs by preschoolers was a disturbing discovery since most of these drugs have not been approved for use in young children by the Federal Food and Drug Administration (FDA). While physicians are permitted to prescribe medications in ways that have not received FDA approval, there is very little data on the possible long-term consequences of using these drugs at such an early age. Further, diagnosing mental illness in children at such a young age is extremely difficult as these children are unable to describe their symptoms adequately, if at all. There was little documentation that appropriate written informed consent to give these medications to minor children was obtained from parents or guardians.

Many records lacked adequate or accurate information, or omitted details on how consent was obtained and what information was provided to children, parents or guardians. SAC also learned that many of these drugs are prescribed by the child's primary care physician and in some cases by more than one physician instead of a psychiatrist who specializes in treating children.

Side effects of these drugs are very serious and include decreased blood flow to the brain, cardiac arrhythmias, disruption of growth hormone leading to suppression of growth in the body and brain of a child, weight loss, permanent neurological tics, dystonia, addiction and abuse, including withdrawal reactions, psychosis, depression, insomnia, agitation and social withdrawal, suicidal tendencies, possible atrophy in the brain, worsening of the very symptoms the drugs are supposed to improve, and decreased ability to learn, tardive dykinesia and malignant neuroleptic syndrome. The FDA is currently reviewing reports of a possible increased risk of suicidal thinking and suicide attempts in children and adolescents under the age of 18 treated with the drug, Paxil.

Because of the growing concern for the health and safety of our children around the country, the Federal Government is now looking at legislation that would authorize the FDA to require pharmaceutical companies to test the effects of drugs on children.

Data Sample

The data contained in this report was obtained from the Department of Children and Family Services district case files, or contracted agents of the department who provide services to foster children. All records reviewed and data extracted were foster care children of the department. The data collected did not meet the requirement of a statistically valid sample, however the data was based on a sample of 1,180 case files. The 1,180 case files that were reviewed were selected using the following criteria: 1) Foster care children in Therapeutic Foster Care Homes; 2) Under the age of 5 years; 3) Once the first two criteria were met the age criteria was increased until the required

number of case files were obtained, and 4) As criteria 1, 2, and 3 were met children outside of Therapeutic Foster Care Homes were looked at until the desired number of cases were met. On the average 76 foster care cases were inspected in each district of the Department of Children and Family Services. The investigative team, when possible, selected cases where the children were most likely on some form of medication.

Data Collection Team

The data collection team for this investigation consisted of Statewide and Local Advocacy Council members and staff from both the Statewide and Local Advocacy Councils. Expertise of the professional investigative team consisted of Medical Doctors, Registered Nurses, Social Workers, Law Enforcement, State Investigators, Mental Health Professionals, Attorneys, and others. All records were reviewed together as to allow the expertise of the team to assist each other when questions were raised. For consistency several of the team members were involved in a number of different data site collection points. One or more experienced team members were at every data collection site. Teams were as few as two and as many as ten members.

Data Collection

A uniform data collection tool was developed by the investigative team leader and reviewed and adopted by the whole team. All data collected came from case files or the foster care worker's "working file" or HomeSafeNet. All data collected was entered into a computer program by one individual for consistency. Cleaned up data consisted of forcing common terms such as "Mom", "Mommy", "Mother", "Birth Mother" and "Maternal Mother" to just "Mother".

Data Analysis

Data analysis was performed by simple tabulation of frequency of occurrence by different fields or multiple fields.

Data Interpretation

The investigation's medical team members reviewed the data and observations. Assessments and conclusions by these members were presented to the full Florida Statewide Advocacy Council for approval.

Additional Data Interpretation

Additional data analysis is to be conducted by the Florida A&M University and the University of Florida, Collage of Pharmacy. This information will be presented in a supplemental report.

Statewide Advocacy Council Findings

Of the 1,180 children reviewed 652 were on one or more psychotropic medications. The remaining number of children, 528, were not on any form of psychotropic medication. The average age of children on psychotropic medications was 12.7 years with the minimum age ranging from less than one year old through the age of seventeen. The average age of children not on psychotropic medications was 7.5 years with the minimum age ranging from less than one year old through the maximum age of seventeen years old.

The average length of time all of the children were in foster care ranged from an average of 8.8 months to a maximum of 166 months. The average length of time in foster care for those children taking psychotropic medications ranged from an average of 11.5 months to a maximum of 120 months. The average length of time in foster care for those children not taking psychotropic medications ranged from an average of 5.5 months to a maximum of 166 months.

Number of Foster Care Children Reviewed by County
Chart 1

County	Number of Children
Alachua	1
Percent	0.08%
Bay	9
Percent	0.76%
Brevard	4
Percent	0.34%
Broward	99
Percent	8.39%
Citrus	2
Percent	0.17%
Clay	6
Percent	0.51%
Collier	44
Percent	3.73%
Columbia	49
Percent	4.15%
Dade	83
Percent	7.03%
Desoto	1
Percent	0.08%
Duval	54
Percent	4.58%
Escambia	2
Percent	0.17%
Flagler	1
Percent	0.08

Number of Foster Care Children Reviewed by County - Cont'd.

Gadsden		3
Percent		0.25%
Hamilton		1
Percent		0.08%
Hillsborough	160	
Percent		13.56%
Indian River	10	
Percent		0.85%
Jefferson		5
Percent		0.42%
Lake		3
Percent		0.25%
Lee		40
Percent		3.39%
Leon		22
Percent		1.86%
Manatee		1
Percent		0.08%
Marion	15	
Percent		1.27%
Martin	23	
Percent		1.95%
Nassau	4	
Percent		0.34%
Okeechobee		8
Percent		0.68%
Orange	33	
Percent		2.80%
Osceola		4
Percent		0.34%
Palm Beach		31
Percent		2.63%
Pinellas		6
Percent		0.51%
Polk		44
Percent		3.73%
Sarasota		26
Percent		2.20%
Seminole		1
Percent		0.08%
St Johns		1
Percent		0.08%
St Lucie		51
Percent		4.32%
Volusia		56
Percent		4.75%
Unknown		277
Percent		23.47%
Grand Total	**1180**	

Number of Children on Psychotropic Medications by County
Chart 2

County	Number of Children
Alachua	1
Percent	0.15%
Bay	9
Percent	1.38%
Brevard	2
Percent	0.31%
Broward	56
Percent	8.59%
Citrus	2
Percent	0.31%
Clay	2
Percent	0.31%
Collier	38
Percent	5.83%
Columbia	10
Percent	1.53%
Dade	8
Percent	1.23%
Desoto	1
Percent	0.15%
Duval	31
Percent	4.75%
Escambia	2
Percent	0.31%
Flagler	1
Percent	0.15%
Gadsden	3
Percent	0.46%
Hamilton	0
Percent	0.00%
Hillsborough	126
Percent	19.33%
Indian River	1
Percent	0.15%
Jefferson	2
Percent	0.31%
Lake	3
Percent	0.46%
Lee	27
Percent	4.14%

Number of Children on Psychotropic Medications by County - Cont'd

County	Number of Children
Leon	21
Percent	3.22%
Manatee	1
Percent	0.15%
Marion	15
Percent	2.30%
Martin	6
Percent	0.92%
Nassau	2
Percent	0.31%
Okeechobee	0
Percent	0.00%
Orange	20
Percent	3.07%
Osceola	0
Percent	0.00%
Palm Beach	25
Percent	3.83%
Pinellas	5
Percent	0.75%
Polk	34
Percent	5.21%
Sarasota	25
Percent	3.83%
Seminole	1
Percent	0.08%
St Johns	1
Percent	0.15%
St Lucie	22
Percent	3.37%
Volusia	50
Percent	7.67%
Unknown	100
Percent	15.34%
Grand Total	**652**

Age in Years Summary for Children on Psychotropic Medications

Chart 3

Age	Number of Children
1	2
Percent	0.31%
2	4
Percent	0.61%
3	1
Percent	0.15%
4	5
Percent	0.77%
5	5
Percent	0.77%
6	17
Percent	2.61%
7	29
Percent	4.45%
8	31
Percent	4.75%
9	35
Percent	5.37%
10	49
Percent	7.52%
11	52
Percent	7.98%
12	51
Percent	7.82%
13	65
Percent	9.97%
14	65
Percent	9.97%
15	63
Percent	9.66%
16	54
Percent	8.28%
17	40
Percent	6.13%
18	43
Percent	6.60%
19	17
Percent	2.61%
20	2
Percent	0.31%
21	1
Percent	0.15%
23	1
Percent	0.15%
Unknown	20
Percent	3.07%
Grand Total	**652**

64 of the case records received and inspected were foster care clients of the Department of Children and Family Services and were covered by Section 409.145(3)(a).

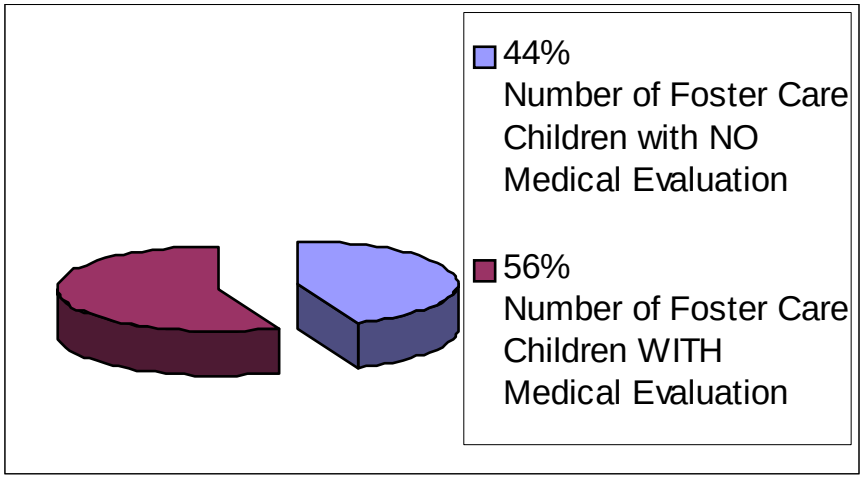
Psychotropic Medications Used in Children Five Years Old and Under

Chart 4

Drug Class	Medication Name	Number of Children	Average Age
Anxiolytic Hypnotic, Non-Benzo	buspirone	1	1.0
Anxiolytic/ Hypnotic, Non-Benzo	pentobarbilal	1	4.0
Atypical Antidepressant	bupropion	1	2.0
Atypical Antidepressant	mirtazapine	1	5.0
Atypical Antipsychotic	risperidone	2	2.0
Benzodiazepines	clonazepam	1	3.0
Benzodiazepines	diazepam	2	2.5
Benzodiazepines	Icrazepam	1	1.0
CNS Stimulants	amphetamine-dextroamphetamine	11	3.6
CNS Stimulants	dextroamphetamine	1	4.0
CNS Stimulants	methyiphenidate	3	3.3
Mania/Bipolar	carbamazepine	2	2.5
Mania/Bipolar	divalproex sodium	1	2.0
Mania/Bipolar	lithium	3	5.0
SSRI	paroxetine	1	5.0
SSRI	sertraline	10	3.0

These records were cause for alarm because of the age of the children. Diagnosing psychiatric illness in children below the age of six is difficult because of the child's inability to accurately and completely describe their feelings.

Number of Children with Medical Evaluation
Prior to Receiving Medications
Chart 5



In many of the records reviewed there was no psychiatric diagnosis or the diagnosis was so vague that it would be difficult to justify the use of psychotropic medications.

Diagnoses for Psychotropic Medications
Chart 6

Diagnosis	Number of Children
Abuse	13
Percent	0.9%
ADHD	310
Percent	22.4%
Adjustment Disorder	46
Percent	3.3%
Anxiety	20
Percent	1.4%
Attachment Disorder	18
Percent	1.3%
Autism	4
Percent	0.3%

Diagnoses for Psychotropic Medications - Cont'd.

Bipolar	80
Percent	5.8%
Borderline Personality Disorder	3
Percent	0.2%
Cerebral Palsy	4
Percent	0.3%
Conduct Disorder	35
Percent	2.5%
Depression	171
Percent	12.3%
Dysthymia	34
Percent	2.5%
Enuresis	21
Percent	1.5%
Hearing Impaired	4
Percent	0.3%
Impulse Control Disorder	27
Percent	1.9%
Intermittent Explosive Disorder	16
Percent	1.2%
Learning Disorder	13
Percent	0.9%
Mental Retardation	43
Percent	3.1%
OCD	2
Percent	0.1%
ODD	99
Percent	7.1%
Psychotic Disorder	17
Percent	1.2%
PTSD	167
Percent	12.1%
Seizure Disorder	10
Percent	0.7%
Substance Abuse	23
Percent	1.7%
Tourettes	3
Percent	0.2%
Other	143
Percent	10.3%
Unknown	59
Percent	4.3%
Grand Total	**1385**

Note: Clients may have multiple diagnoses

Diagnosis by Age
Chart 7

Diagnosis	# of Children	Avg. Age	Min. Age	Max. Age
Abuse	13	13.4	13	18
Percent	0.9%			

ADHD Percent 22.4%	310	11.7	1	21
Adjustment Disorder Percent 3.3%	46	12.9	6	21
Anxiety Percent 1.4%	20	12.5	4	19
Attachment Disorder Percent 1.3%	16	10.7	4	16
Autism Percent 0.3%	4	14.5	11	18
Bipolar Percent 5.8%	80	14.3	2	23
Borderline Personality Disorder Percent 0.2%	3	16.0	16	16
Cerebral Palsy Percent 0.3%	4	13.3	11	16

Diagnosis by Age - Cont'd.

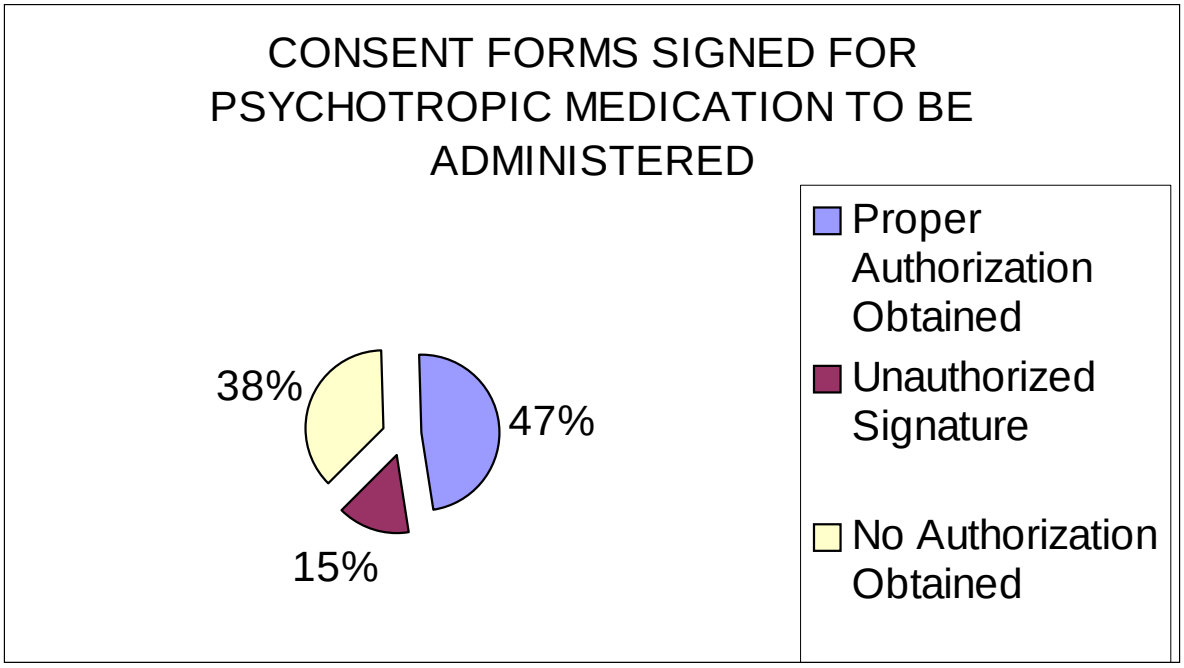
Diagnosis	# of Children	Avg. Age	Min. Age	Max. Age
Conduct Disorder Percent 2.5%	35	14.9	6	20
Depression Percent 12.3%	171	14.0	2	23
Dysthymia Percent 2.5%	34	14.4	2	18

Enuresis	21	12.6	2	19
Percent 1.5%				
Hearing Impaired	4	16.5	14	18
Percent 0.3%				
Impulse Control Disorder	27	12.8	4	21
Percent 1.9%				
Intermittent Explosive Disorder	16	14.3	10	18
Percent 1.2%				
Learning Disorder	13	13.1	6	16
Percent 0.9%				
Mental Retardation	43	13.6	8	18
Percent 3.1%				
OCD	2	12.5	10	15
Percent 0.1%				

Diagnosis by Age - Cont'd.

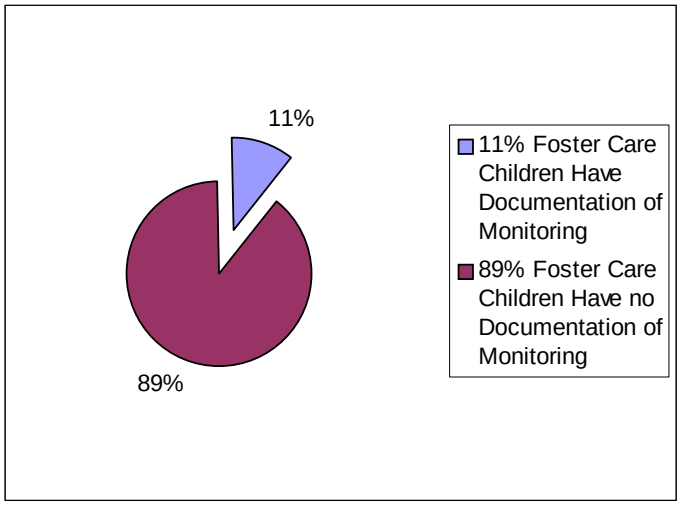
Diagnosis	# of Children	Avg. Age	Min. Age	Max. Age
ODD Percent 7.1%	99	12.4	2	19
Other Percent 10.3%	143	12.8	2	19
Psychotic Disorder Percent 1.2%	17	14.3	9	19
PTSD Percent 12.1%	167	12.6	2	23
Seizure Disorder Percent 0.7%	10	13.1	2	17
Substance Abuse Percent 1.7%	23	16.2	1	20
Tourettes Percent 0.2%	3	12.7	10	15
Unknown Percent 4.3%	59	23.8	3	19

Consent Forms Summary
Chart 8

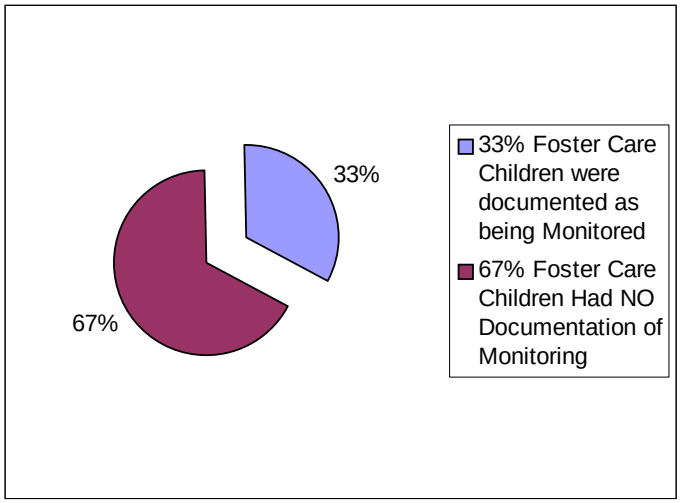


The files contained signed blank consent forms. Some of the signed forms contained blanks in the pertinent and most applicable fields of the form. Many of the blank forms were signed by individuals who do not have legal authority to do so. This included physicians, DCF staff, foster care counselors and foster care parents without termination of parental rights.

Number of Foster Care Children with Known Tardive Dyskinesia* Monitoring
Chart 9



Number of Foster Care Children Monitored for Side Effects
Chart 10



*****-Tardive Dyskinesia (TD) - A central nervous system disorder characterized by twitching of the face and tongue and involuntary motor movement of the trunk and limbs and occurring episodes as a side effect of prolonged use of anti-psychotic drugs.

Reference: Merriam Webster Medical Book Dictionary 1996

Number of Children on PRN Psychotropic Medications by Class
Chart 11

Drug Class	Medication	Number of Children
Antipsychotic		
	chlorpiormazine	23
	haloperidol	20
	prochlorperazine	1
Sum		44
Percent		42%
Anxiolytic/Hypnotic, Non-Benzo		
	hydroxyzine	21
Sum		21
Percent		20%
Atypical Antidepressant		
	bupropion	1
	trazodone	4
Sum		5
Percent		5%
Atypical Antipsychotic		
	olanzapine	2
	quetiapine	1
	risperidone	1
Sum		4
Percent		4%
Benzodiazepines		
	chlordiazepoxide	1
	clonazepam	1
	diazepam	2
	lorazepam	25
Sum		29
Percent		27%
CNS STimulants		
	amphetamtne-Dextroamp	1
	methylphenidate	1
Sum		2
Percent		2%
Mania/Bipolar		
	valproic acid	1
Sum		1
Percent		1%
Grand Total		**106**

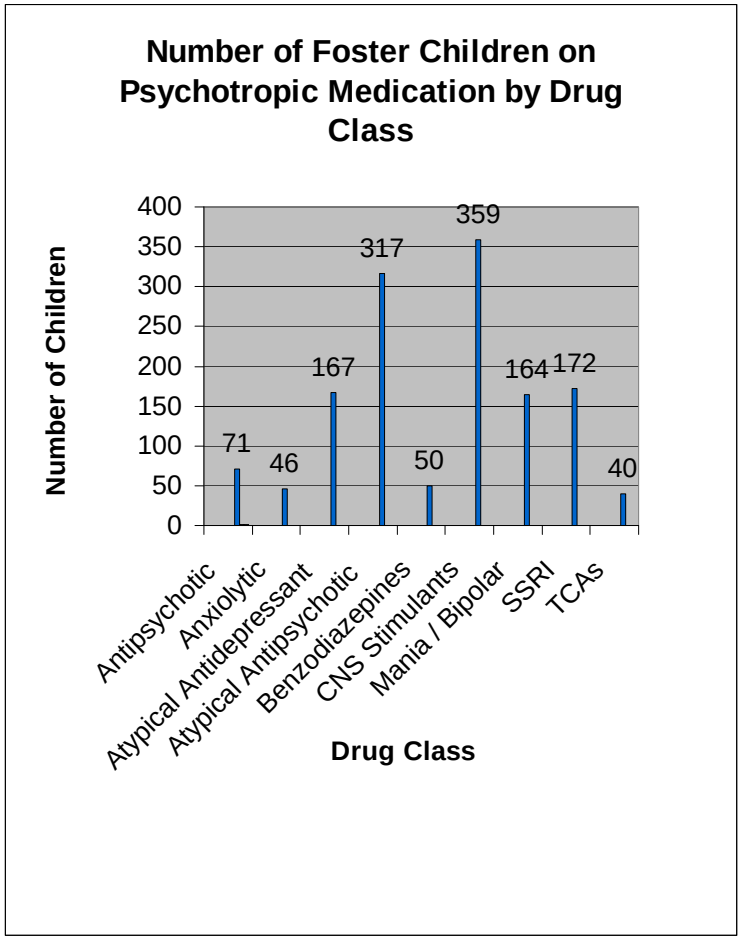
Drug Class Utilization Summary
Chart 12

Drug Class	Medication	Number of Children
Antipsychotic		
	chlorpromazine	31
	haloperidol	34
	mesoridazine	1
	prochlorperazine	2
	thioridazine	8
	trifluoperazine	3
Sum		79
Percent		5.2%
Anxiolytic/ Hypnotic, Non-Benzo		
	buspirone	6
	hydroxyzine	40
	pentobarbital	1
Sum		47
Percent		3.1%
Atypical Antidepressant		
	bupropion	86
	mirtazapine	28
	nefazodone	4
	trazodone	33
	venlafaxine	27
Sum		178
Percent		11.7%
Atypical Antipsychotic		
	clozapine	2
	olanzapine	72
	quetiapine	85
	risperidone	189
	ziprasidone	10
Sum		356
Percent		23.6%
Benzodiazepines		
	Alprazolam	2
	chlordiazepoxide	1
	clonazepam	11
	diazepam	3
	lorazepam	36
Sum		53
Percent		3.5%

Drug Class Utilization Summary – Cont'd

Drug Class	Medication	Number of Children
CNS Stimulants		
	dextroamphetamine	201
	dexmetylphenidate	1
	dectinamphetamine	31
	methylphenidate	166
	pemoline	1
Sum		406
Percent		26.4%
Manic/Bipolar		
	carbamazepine	16
	divalproex sodium	123
	lithium	8
	valproic acid	6
Sum		173
Percent		11.4%
SSRI		
	citalopram	24
	fluoxetine	33
	fluvoxamine	8
	paroxetine	56
	sertraline	69
Sum		196
Percent		12.5%
TCAs		
	amitriptyline	2
	desipramine	2
	doxepin	1
	imipramine	27
	nortriptyline	8
Sum		40
Percent		2.6%
Grand Total		1518

Drug Class Summary
Chart 13



Statewide Advocacy Council Recommendations

- Develop and implement a quality assurance program for monitoring the use of these drugs in children. Such a system would ensure that appropriate attempts at behavior management were implemented and that the prescribing of drugs is a last resort.
- Develop a Plan of Care to include counseling for anger, self-esteem, positive reinforcement, dealing with fear and attitude, and character building traits. Not all foster children will need this counseling but it should be available for those that do.

- Ensure that appropriate standardized written informed consent is obtained prior to starting any child on psychotropic medication. This consent should include information about any risks and expected benefits, including possible side effects and alternative treatments.
- Ensure that everyone who administers psychotropic medications to children in a foster care setting is trained to recognize the side effects of medications.
- Ensure that pediatric psychiatrists perform medical examinations prior to implementation of these drugs. These doctors understand and recognized potential side effects of these drugs when used in children.
- Ensure that foster care records for each child contain organized information and that medical records are easily found.
- Ensure when more than one physician is ordering medications that Medical Passports are current and made available to each physician.

Conclusion

It is imperative that the foster care children in the State of Florida receive the necessary medical treatment they need, however, unnecessary dispensing of psychotropic medication remains a threat to them. Until there is more information regarding the safety and efficiency of these drugs, Florida's foster care children should be monitored closely. The information in this report should be immediately incorporated into an agenda in order to preserve and protect the health, safety, welfare and rights of children in foster care.

Public Records

A copy of this Red Item Report and other SAC materials, *including the General Work Plan FY 2003 and the Annual Report to the Florida Legislature may be accessed at the following address:*

Office of the Executive Director, Florida Statewide Advocacy Council, 1317 Winewood Boulevard, Building 1, Suite 401, Tallahassee, Florida 32399-0700, Telephone No. 850.488.6173, SUNCOM No. 278.6173, Facsimile No. 850.922.5312, e-mail: Marvin_William@dcf.fl.state.us

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