Misuse of Psychotropic Medication in Foster Care:
Improving Child Welfare Oversight and Outcomes within the Continuum of Care

A Joint Oversight Hearing of the Senate Human Services Committee and
the Senate Select Committee on Mental Health

Senator Mike McGuire, Chair, Senate Human Services
Senate Jim Beall, Chair, Select Committee on Mental Health

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State Capitol Room 3191

Introduction:

California is home to more than 63,000 foster youth who have been removed from their homes
as a result of traumatic life events usually involving severe abuse and neglect. Studies show that
children who come into contact with child protective services are likely to experience numerous
"adverse experiences" including physical, mental and emotional maltreatment, family
dysfunction, drug use, involvement in the criminal justice system, adult mental health,
homelessness, domestic violence, among others. Moreover there is growing evidence that a
child's removal from home is itself a direct cause of trauma, and frequent placement changes
exacerbate the impact. These childhood traumas often lead to enduring mental and emotional
health challenges due a variety of changes in brain structure and function, as well as stress-
responsive neurobiological systems.

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1 Ensuring Safety, Well-Being and Permanency for Our Children. University of North Carolina, Chapel Hill Injury
Prevention and Research Center.

2 http://tucollaborative.org/pdfs/Toolkit%20Monographs%20Guidebooks/parenting/Factsheet_4_Resulting_Trauma.pdf

effects of childhood abuse and related experiences: A convergence of evidence from neurobiology and
California’s child welfare system, in assuming responsibility as the acting “parent” for dependent children, seeks to provide a continuum of placement settings, services and supports for children and their biological and foster families. However, far too often divisions and competing priorities between local child welfare, mental health, and education systems lead to insurmountable barriers to effectively serving these children who are profoundly in need of stability, love and healing. A lack of access to a system of care that addresses the trauma that a child experiences leaves these children at greater risk for acute behavioral and mental health challenges for which medication is seen as the only available treatment option. This hearing will discuss overprescribing of psychotropic medication in this context, will identify important tools for safeguarding the health of youth receiving these drugs, and most importantly will highlight promising systems of care to meet the needs of all kids who have experienced the trauma of being removed from their homes.

A recent series of stories published in the San Jose Mercury News\(^4\) and most recently in the Los Angeles Times, highlighted growing concerns that psychotropic medications have been relied on by California’s child welfare and children’s mental health systems as a means of controlling, instead of treating, youth who suffer from trauma-related behavioral health challenges. The series detailed significant challenges in accessing pharmacy benefits claims data held by the California Department of Health Care Services (DHCS), eventually overcome through a Public Records Act request and lengthy negotiations, and demonstrated that prescribing rates that were far higher than had been anticipated by child welfare system experts.

Additionally, the San Jose Mercury News series highlighted a ProPublica investigation finding that drug-makers provided gifts and payments to 908 of California’s 1,647 foster care psychotropic medication prescribers in amounts that were more than double what they gave to the typical California physician. Additionally, it was found that high prescribers were targeted with the highest payments, leading to concerns that such a financial relationship with physicians may influence prescribing decisions. Further, the series highlighted U.S. Department of Justice prosecutions against some drug-makers related to illegal marketing of anti-psychotic medications for use in children, despite the lack of clinical research supporting their use in this population, and despite evidence of serious life altering side-effects.

**Psychotropic Medication in Foster Children**

An expanding array of powerful anti-psychotics and other psychotropic medications have been prescribed, and in some cases illegally marketed, for off-label use for children and adolescents to moderate challenging behaviors health disorders. Over the last fifteen years, prescribing rates of psychotropic medications for California’s foster youth have steadily increased, from less than 1 percent of foster youth receiving such medications in 2000, to nearly 15 percent of all foster

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youth today.\textsuperscript{5} When adjusted to account only for adolescent foster youth, prescribing rates rise to nearly 1 in 4 youth, and 56 percent of all youth residing in group homes were prescribed at least one psychotropic medication. Furthermore, for those youth prescribed psychotropic medications, nearly 60 percent were prescribed an anti-psychotic – the powerful drug class most associated with debilitating side effects, and 36 percent were prescribed multiple medications, also referred to as “polypharmacy.”\textsuperscript{6} Increases observed in California mirror those across the nation - children in foster care represent only three percent of children covered by Medicaid, yet, a study of pharmacy claims in 16 States showed that foster children enrolled in Medicaid were prescribed antipsychotic medications at nearly nine times the rate of other children receiving Medicaid.\textsuperscript{7}

Concern over the use of psychotropic medications among children has been well-documented in research journals and the mainstream media for more than a decade. The category of psychotropic medication is fairly broad, intending to treat symptoms of conditions ranging from ADHD to childhood schizophrenia. Some of the drugs used to treat these conditions are FDA-approved, including stimulants like Ritalin for ADHD, however only about 31 percent of psychotropic medications have been approved by the U.S. Food and Drug Administration (FDA) for use in children or adolescents. It is estimated that currently more than 75 percent of the prescriptions written for psychiatric illness in this population is “off label” in usage, meaning they have not been approved by the FDA for the prescribed use, though the practice is legal and common across all manner of pharmaceuticals.\textsuperscript{8}

In 2003, the FDA released a public health advisory identifying a risk of increased suicidal thoughts and attempts in clinical trials of antidepressants in the pediatric population.\textsuperscript{9} In 2008, the American Academy of Pediatrics and the American Hospital Association issued a joint advisory expressing concern over a small increase in sudden death from adverse cardiac events in children taking stimulants. The advisory recommended a physical exam and expanded patient and family health history focusing on cardiovascular disease risk factors, and an electrocardiogram (EKG) at the physician’s discretion for children being prescribed stimulants. Additional studies have documented appetite suppression related to stimulant use, and in pediatric patients they have been associated with decreasing growth velocity, especially when children are on higher doses.\textsuperscript{10}

\textsuperscript{5} Child Welfare Indicator Project, UC Berkeley
\textsuperscript{6} National Center for Youth Law analysis of data provided by California Department of Health Care Services

\textsuperscript{7} Crystal, S; Olsson, M; Huang, C; Pincus, H; & Gerhard, T. (2009). Broadened use of atypical antipsychotics: Safety, effectiveness, and policy challenges. Health Affairs, 28(5):770. (http://content.healthaffairs.org/content/28/5/w770.full.html)

\textsuperscript{8}https://www.magellanprovider.com/mhs/mgl/providing_care/clinical_guidelines/clin_monographs/psychotropicdrugsinkids.pdf

\textsuperscript{9} Ibid.
\textsuperscript{10} Ibid.
Anti-psychotic medications, used to treat more severe mental health conditions, include powerful brand-name drugs such as Haldol, Risperdal, Abilify, Seroquel and Zyprexa. They have very limited approval by the FDA for pediatric use beyond rare and severe conduct problems that are resistant to other forms of treatment, such as Tourette’s syndrome, behavioral symptoms associated with autistic disorder, childhood schizophrenia, and bipolar disorder.\textsuperscript{11} However, the off-label use of these anti-psychotics among children is high, particularly among foster children. According to a study published in 2011, children who took antipsychotic medications were likely to suffer ill health effects including “cardiometabolic and endocrine side-effects” as well as significant weight gain.\textsuperscript{12} The authors recommended that collaboration between child and adolescent psychiatrists, general practitioners and pediatrician is essential to “reduce the likelihood of premature cardiovascular morbidity and mortality.”

Compounding the potential for unintended side effects is the use of combinations of psychotropic medications, despite limited evidence of clinical efficacy, which foster youth are particularly likely to be prescribed.\textsuperscript{13} Protecting the health and well-being of children on one or more psychotropic medication requires extensive and ongoing health and metabolic screenings to identify potential adverse effects quickly, however in practice many children many fail to receive ongoing screenings and adverse effects may go undetected causing permanent injury or death.

The American Academy of Child and Adolescent Psychiatry, in its “Guide for Community Child Serving Agencies on Psychotropic Medications for Children and Adolescents” writes that “medications are only one component of a comprehensive biopsychosocial treatment plan that must include other components in addition to medication.” According to the guide, many youth benefit from psychotropic medication, allowing them to remain in their homes and make better use of community treatment interventions, though medication “may be over-prescribed when there is insufficient attention paid to other supports and services” and medication may also be under-prescribed when there is a lack of access to a qualified mental health professional with expertise in children’s psychopharmacology. Additionally, the guide writes that “active pursuit of alternative interventions to medications are especially important when there are serious side effects that can occur, such as weight gain or movement disorders, especially when medicine is prescribed over an extended period of time.”

**Federal and State Responses**

The national trend toward increased prescribing of psychotropic medications led the federal government to express concern “about the safe, appropriate, and effective use of psychotropic


\textsuperscript{13} http://www.ncbi.nlm.nih.gov/pubmed/25022817
medications among children in foster care." Recent federal legislation requires state agencies to develop a plan for ongoing oversight and coordination of health care services for children in foster care "to ensure that children in foster care receive high-quality, coordinated health care services, including appropriate oversight of any needed prescription medicines" and requires the plan include protocols for the appropriate use and monitoring of psychotropic medications.

Importantly, recent correspondence from the U.S. Department of Health and Human Services highlights the emerging "wellness oriented" model of care for children in foster care which integrates a deeper understanding of the neurological impact of trauma on developing children and its implications for overall social and emotional wellbeing. The letter notes that 90 percent of children in foster care are exposed to complex trauma.

"Many of these children will demonstrate complex symptoms and/or behaviors that may not map directly to the Diagnostic and Statistical Manual of Mental Disorders (DSM) or the International Classification of Diseases (ICD). For example, there is currently no DSM diagnosis that adequately captures the range of child trauma effects. Many children who have experienced complex trauma will not meet the criteria for a diagnosis of Post-Traumatic Stress Disorder (PTSD). Yet, trauma-related symptoms are identifiable, can be clinically significant and can be addressed with appropriate interventions. For these children, appropriate screening, assessment and referral to evidence-based practices are clearly indicated...There is reason to believe that such widespread and at times problematic use of [psychotropic] drugs is a reaction to the clinical complexity of symptoms among children exposed to complex trauma and the lack of appropriate screening, assessment and treatment."

In response to expanding federal requirements, the departments of Health Care Services (DHCS) and Social Services (CDSS) has established the "Quality Improvement Project” (QIP) to enhance psychotropic medication safety; support the use of psychosocial counseling in lieu of medications; reduce the inappropriate concurrent use of multiple psychotropic medications; engage medication prescribers through education and consultation; increase the use of electronic health records; use data to analyze, monitor and oversee the safe use of medication; and actively engage foster youth in their care through education. The QIP project began meeting with stakeholders in early 2014 and is expected to continue through 2015.

In 2006, DHCS instituted a requirement that all prescriptions of antipsychotics for children under 6 years of age on Medi-Cal would require the submission of a Treatment Authorization Request.

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15 Fostering Connections to Success and Increasing Adoptions Act of 2008. (Public Law 110-351 (section 422(b)(15))
16 Child and Family Services Improvement and Innovation Act (P.L. 112-34) (section 422(b)(15)(A))
(TAR) prior to approval. In October of 2014, the TAR requirement was expanded to include antipsychotic medications for all youth age 0-17. This process has been controversial among prescribers who state it is burdensome and costly. Data provided by DHCS indicates that 11 percent of TARs for this purpose are denied, and 75 percent are approved. The remaining were deferred, with approximately 33 percent of those deferred being subsequently approved.

In 2007, California established the California Mental Health Care Program (CalMEND) Performance Improvement Project Learning Collaborative as a pilot project involving DHCS and mental health departments of Alameda, Marin, Orange, and Stanislaus. The pilot tested and implemented a set of quality improvement performance measures and indicators for prescribing of antipsychotics in adult populations. The pilot developed and tested quality indicators including the use of two or more antipsychotic medications, and whether prescribing was within therapeutic dosing parameters. It also considered the frequency of prescription refills, multiple prescribers for individual beneficiaries; and it evaluated the age, ethnicity and gender of beneficiaries receiving these medications. According to the department, DHCS continued to provide data support to some counties following completion of the project in 2009.

However, since 2010 participating counties stopped requesting DHCS data or allowed the data use agreements to expire without renewal. Federal correspondence specifically highlighted the use of drug utilization review programs, such as CalMEND, as an important oversight tool. The legislature may wish to investigate this model of oversight in the future.

Continuum of Care Reform Efforts

In response to SB 1013 (Committee on Budget and Fiscal Review, Chapter 35, Statutes of 2012), CDSS led a three-year effort involving numerous stakeholder groups that resulted in a recently released report entitled “California’s Child Welfare Continuum of Care Reform.” This report seeks to outline a comprehensive approach to improving California’s child welfare system by reforming the system of placements and services directed at youth in foster care. The report outlines a number of bold reforms that, if implemented, may have a significant impact on rates of psychotropic medication use in foster care.

Specifically, in the report, new models of care for foster youth are envisioned. These include providing all foster youth with access to a child and family team – instead of relying solely on a single social worker – and empowering those child and family teams to utilize a more consistent assessment tool that identifies the needs of the child. Rather than leaving a child to fail upwards into a group home before the child is provided more intensive services, the report envisions providing needed treatment and services in homes, and relying on group homes only for short-term treatment placements. Currently many critical services are inconsistently available, often only to foster youth who qualify for heightened services, or who are placed in group homes. Many of the policy recommendations reflected in the report mirror those the federal government has identified as helpful to address overprescribing of psychotropic medications.
California Child Welfare System

California has a complex child welfare system incorporating federal, state and local funds expended for the broad purpose of child welfare, including child abuse prevention and response. The federal Administration of Children and Families (ACF) administers numerous federal grants intended to assist states with child abuse prevention and response and to support the foster care system which provides board and care payments for eligible dependent children. Within the statutorily established parameters for each grant, states have substantial flexibility in how to apportion funds but are accountable to significant federal oversight of program administration.

CDSS supervises the 58 county-administered Child Welfare Services systems that investigate approximately 32,000 reports of abuse and neglect of children annually. According to CDSS, as of January 2015, there were nearly 63,000 children in foster care placement, with nearly one in three residing in Los Angeles County. Following a court order to remove a child from parental custody, existing law requires the court to order the care, custody, control and conduct of the child to be under the supervision of the social worker.\textsuperscript{18} However existing law also provides that only a juvenile court judicial officer has the authority to make orders for the administration of psychotropic medications for a dependent child.

Court oversight mechanisms

In 1999, California passed SB 543 (Bowen, Chapter 552, Statutes of 1999) which mandated that once a child has been adjudged a dependent of the state only the court may authorize psychotropic medications for the child, based on a request from a physician that includes the following:\textsuperscript{19}

- The reasons for the request;
- A description of the child’s diagnosis and behavior;
- The expected results of the medication;
- A description of any side effects of the medication.

Under the statute, psychotropic medications are defined as those “administered for the purpose of affecting the central nervous system to treat psychiatric disorders or illnesses. These medications include, but are not limited to, anxiolytic agents, antidepressants, mood stabilizers, antipsychotic medications, anti-Parkinson agents, hypnotics, medications for dementia, and psychostimulants.”

In accordance with this statute, the Administrative Office of the Courts established a series of court documents generally referred to as “the” JV 220, which includes a statement completed and signed by the prescribing physician that includes the child’s diagnosis, relevant medical

\textsuperscript{18} WIC 361.2
\textsuperscript{19} WIC 369.5
history, other therapeutic services, the medication to be administered, and the basis for the recommendation.

In addition, a form must be included indicating notice has been provided to the parents or legal guardians, their attorneys of record, the child's attorney of record, the child's guardian ad litem, the child's current caregiver, the child's Court Appointed Special Advocate, if any, and if a child has been determined to be an Indian child, the Indian child's tribe. The procedure for notification varies by county – the responsibility may fall primarily to the child welfare agency, or it may be shared with the juvenile court clerk’s office that may be responsible for notifying the attorney and the Court Appointed Special Advocate.

Within four court days after notification, a parent or guardian, the child, the attorney for either, the guardian ad litem, or the Indian child’s tribe may file an objection to the application. Following this period, the court files a final order.

Stakeholders here expressed widespread concerns about the efficacy of this oversight, given that in many counties the court lacks access to medical experts to assist in evaluating medical information. Child welfare advocates and clinicians report that in many instances a prescribing physician who fills out the form may not have a history of treating the child, and thus may not be aware of prior medications or alternative treatments that have (or have not) been tried. In theory, a health and education passport – a paper file of the youth’s medical history – is supposed to be provided to a new caregiver; however it is common for a child to move between placements without the requisite records, leaving the foster parent unaware of the child’s medical history.

Furthermore, the JV 220 form offers little opportunity for input from the community of representatives and caregivers involved with the youth except to offer a short window of opportunity to formally object. In practice, there is little evidence that the JV 220 process has led to changing prescribing practices or trends.

One strategy to improve the relevance of the JV 220 process has been the use of clinical staff as consultants to the court. In Los Angeles County, the Department of Mental Health provides two clinical staff to review every JV 220 request that is considered by the court. Their effectiveness may hindered due to the limited information available to them on the JV 220 form. The form does not include information related to baseline or ongoing screening, it does not require consideration of alternative treatments (though it provides a field inquiring about them), nor does it offer substantive opportunities for relevant parties to weigh in with important information that may be worthy of consideration by the court. Presiding Los Angeles Juvenile Court Judge Michael Nash, in a 2012 court memorandum suggested that providing these staff with access to the electronic case management system used by social worker might improve their effectiveness.

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20 See also 25 U.S.C. § 1903(4)-(5); Welf. and Inst. Code, §§ 224.1(a) and (e) and 224.3.
Also in Los Angeles County, a memorandum was provided to the county Departments of Child and Family Services and Probation, requiring that placement changes be accompanied by a report to the court containing answers to very detailed questions, underscoring the very practical challenges that social workers, caregivers, and foster youth may face in monitoring psychotropic medications when changing placements. A handful of the numerous questions include:

- Did a supply of medication traveled with the child/youth (to avoid an interruption)?
- Has the new caregiver been fully informed of the medication regimen and been provided a copy of the medication authorization form?
- Has the new caregiver been given the name and contact information of the treating physician and informed whether there are upcoming appointments?
- Will a change of physician be necessary?
- What is the plan for maintaining any other services/treatments that the child is receiving?
- Has the new caregiver been given a copy of the youth’s health and education passport?

**Additional Oversight Measures**

Many states have implemented red flag and response mechanisms as part of their psychotropic medication oversight and monitoring systems. This model identifies high-risk situations that warrant additional scrutiny. Some potential indicators include:

- Use of antipsychotic medications in children under 6 years of age;
- Use of high doses of antipsychotic medications;
- Use of multiple antipsychotic or psychotropic medications during a calendar year;
- Maximum gap in days between psychotropic drug claims.

Additionally, following a court order approving medications, there is a need for ongoing assessment and screening prior to the next court hearing. Many counties utilize public health nurses to consult with child welfare social workers for this purpose, however the practice and scope of their involvement with foster youth is inconsistent across the state.

**Mental Health Services for Foster Youth**

A principal point of access for mental health services for foster youth is though specialty Medi-Cal mental health services, provided by county-operated mental health plans. County mental health plans may provide mental health services directly, or by contracting with local providers.

Foster youth, like all children enrolled in Medi-Cal, are eligible for the Early Periodic Screening Diagnosis and Testing (EPSDT) benefit. This uncapped entitlement provides for periodic

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[21](http://www.chcs.org/resource/red-flags-response-systems-oversight-monitoring-psychotropic-medications-wyoming-maryland/)

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screenings to determine a child’s medical needs and, based upon the identified health care need, treatment services are to be provided. EPSDT mental health services provide Medi-Cal enrolled children access to a continuum of mental health services including:

- Mental health assessment;
- Crisis Intervention/Stabilization;
- Day Rehabilitation/Day Treatment Intensive;
- Intensive Care Coordination;
- Medication support services;
- Targeted case management;
- Therapeutic behavioral services.

EPSDT provides children with a benefit at an exceptionally high standard of care. According to the U.S. Department of Health and Human Services:

“While there is no federal definition of preventive medical necessity, federal amount, duration and scope rules require that coverage limits must be sufficient to ensure that the purpose of a benefit can be reasonably achieved.... Since the purpose of EPSDT is to prevent the onset of worsening of disability and illness and children, the standard of coverage is necessarily broad... the standard of medical necessity used by a state must be one that ensures a sufficient level of coverage to not merely treat an already-existing illness or injury but also, to prevent the development or worsening of conditions, illnesses, and disabilities.”

In many counties, foster youth may also access mental health benefits through a managed care plan, which may screen for mental health needs and refer a foster youth to a provider directly, or to a county mental health plan.

California’s system of children’s mental health care is highly fragmented with significant geographic gaps in access to services as each county prioritizes resources and develops its network of providers with little oversight or statewide standards. Stakeholders widely describe the limited availability and scope of county mental health services for children despite repeated assurances from the DHCS and county mental health departments that services are available to all children who meet very broad medical necessity criteria under EPSDT.23

Foster youth, caregivers, community service providers and advocates report that although a foster youth has been assessed as being in need of mental health services, he or she often “does not qualify” for a particular service and is often turned away. This is often because the youth’s level of severity may not meet the level of need for the particular service that has been offered. Thus, it is not until a youth is exhibiting more acute symptoms that the child accesses services. Additionally, foster youth and their advocates commonly express challenges accessing the

22 http://mchb.hrsa.gov/epsdt/mednecessity.html
23 http://www.kidsdata.org/topic/64/special-needs-referral-difficulty/table?fmt=323&loc=1774.2&fth=74&eh=136.135
mental health benefits that EPSDT should entitle the youth to receive, citing waitlists, or a lack of capacity.

This persistent disconnect between the anecdotal experience of a multitude of child welfare social workers, dependency attorneys, court appointed special advocates, advocacy community organizations, foster parents, and foster youth may arise due to a lack of interdepartmental problem solving between child welfare agencies, county mental health departments and the state, including the DHCS and the CDSS.

Katie A. Settlement

Recently, the state settled the Katie A. v Bonta case, a lawsuit filed on behalf of children in California who are in foster care or at imminent risk of foster care placement, have a documented mental health need, and who need certain individualized mental health services to treat or ameliorate their illness or condition. The lawsuit centered on a finding that certain foster youth who meet the medical necessity criteria for Specialty Mental Health Services or EPSDT were not receiving the mental health benefits for which they were eligible.

In response, the state of California has agreed to establish three new Medi-Cal specialized mental health services aimed at meeting the needs of the youth who are covered under the settlement. In fulfilling the obligations of the settlement, DHCS and CDSS have drafted a Core Practice Model to provide guidance and establish a standard of care for county child welfare and mental health agencies, and other service providers that provide services to youth covered under the settlement. The departments have jointly released two documents – a “Core Practice Model Guide” and a “Medi-Cal Manual for Intensive Care Coordination, Intensive Home Based Services and Therapeutic Foster Care.” However, it is notable that these services are targeted at youth exhibiting significant mental health challenges, and do not address the consistent lack of trauma informed mental health services aimed at serving youth who exhibit indicators of trauma, but have yet to develop severe symptoms.

Group Homes

Group homes are 24-hour residential facilities licensed by CDSS to provide board and care to foster youth from both the dependency and delinquency jurisdictions. Group home facilities are organized under a system of rate classification levels (RCLs) ranging from 1-14 that are based on levels of professional training and adult-to-child ratios. In practice, the majority of group homes are RCL 10 and above, with reimbursement rates ranging from $7,000 to nearly $10,000 per child per month (excluding mental health contracts).

24 “Medi-Cal Manual for Intensive Care Coordination (ICC), Intensive Home Based Services (IHBS) and Therapeutic Foster Care (TFC) for Katie A. Subclass Members.” DHCS and CDSS, 2013.
While in a group home program, children are intended to receive services and treatment designed to eliminate or reduce the conditions, behaviors and characteristics that led to their group home placement, and to teach new, more adaptive skills and behavior. To that end, group homes are required to establish a “group home program statement” that includes a training plan that is appropriate for the client population and the training needs and skill level of child care staff. Through regulation, existing law provides that newly hired staff complete at least 24 hours of training within 90 days of being hired, and 40 hours within 12 months, as specified, with all existing staff receiving 20 hours annually. Regulations provide for the minimum topics that must be included (e.g. discipline policies and procedures, behavior problems/psychological disorders, and mental health/behavioral interventions). Social work staff are required to establish a "needs and services plan" for each child that identifies the specific needs of an individual child, and delineates those services necessary in order to meet the child’s identified needs. Additionally, group homes are required to develop an emergency interventions plan to address aggressive or assaultive behavior of residents.26

While, 56 percent of youth residing in group homes have been prescribed psychotropic medication, it is unknown whether there is significant variation of prescribing rates among group home providers with similar population demographics. Although CDSS does not assess group home provider performance or outcomes based on psychotropic medication rates, such indicators may be useful in determining whether the group home program statement, intervention plan, and implementation of children’s needs and services plans are sufficient to meet the needs of youth, or are being implemented properly.

Continued Data Development

Among other things, the Quality Improvement Project is working to compile relevant data indicators to evaluate psychotropic medication use in foster care. In that regard DHCS and CDSS hold monthly meetings with stakeholders to negotiate the parameters of the data for use in agreed-upon indicators. For this purpose, data from CWS/CMS on youth in foster care is matched with a dataset containing fee-for-service and Medi-Cal managed care encounter data pharmacy paid claim records for psychotropic medication for children in foster care to identify prescribing patterns.

In addition to understanding prescribing patterns for psychotropic medication, data from the Short/Doyle Medi-Cal (SD/MC) claiming system may be useful for the state to assess whether foster youth are accessing nonpharmaceutical specialty mental health services, such as cognitive behavioral therapy as an alternative to, or in addition to, psychotropic medications.

26 Title 22 CCR 84322
The process of identifying accessible data and establishing indicators has been controversial. For several years, DHCS has cited privacy concerns related to the Health Information Portability and Accessibility Act (HIPAA) in rejecting pharmacy claims data that was requested by National Center for Youth Law. However, following submission of a public records act request from the San Jose Mercury News, the department began providing the pharmacy claims data regarding psychotropic medications.

The department states that recent changes to HIPPA established both civil and criminal penalties for releasing data that is not adequately de-identified, which apply not only to the agency, but also personally to the staff that may be involved. This led the department to develop a set of guidelines\(^{27}\) to provide a consistent set of processes used to evaluate data for public release that take into account the data to be included and other publicly available information that could be used in combination with its data to personally identify individuals.

The department also noted that, although public release data is subject to the strict guidelines the department has implemented in interpreting HIPPA, it could provide the data to research institutions under data use agreements under which the receiving entity agrees to comply with the privacy guidelines set forth by the department as well as other conditions in order to receive more complete access to available data.

As a result of HIPPA privacy concerns identified during conversations with legislative staff a week before this hearing, CDSS restricted the CWS/CMS data set related to psychotropic medication use in foster care that had been previously made public online. A month earlier the Department had added data pertaining to probation youth. The department now cites HIPPA as a barrier to providing county, age, gender, and race specific data related to psychotropic medications. Such limitations in sharing important data publicly pose significant challenges to child welfare advocates attempting to understand the scope of the problem.

\(^{27}\) Public Aggregate Reporting for DHCS Business Reports (PAR-DBR) Guidelines