

The Financial and Societal Costs of Medicating America's Foster Children

Testimony of

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Good morning Chairman Carper, Ranking Member Brown, and distinguished members of the Committee. My name is Matt Salo, and I am the Executive Director of the National Association of Medicaid Directors (NAMD). We appreciate the opportunity to testify before you today on an issue of critical importance in our health care system.

Medicaid

Medicaid is the nation's health care safety net. Jointly financed by the states and the federal government, Medicaid will spend more than \$400 billion this year to provide health care to more than 60 million Americans. The program is administered by the states within a broad federal framework which leads to enormous variation across states in terms of who is covered, what services are provided, and how those services are delivered and paid for. Furthermore, within any given state, Medicaid's role is broad, varied, and complex. Medicaid funds more than 40 percent of all births, and the majority of all publicly financed long-term care in this country. It also provides most of the nation's funding for HIV/AIDS related treatments, mental health services, and others. It is therefore very difficult to talk simplistically about Medicaid (either nationally, or within a state), despite its incredible importance in the U.S. health care system.

NAMD is a newly formed organization created with the sole purpose of providing a home for the nation's Medicaid Directors and we represent all 56 of the state, territorial and DC agency heads. Our two broad objectives are to give the Medicaid Directors a strong, unified voice on national and federal matters as well as helping develop a robust body of technical assistance and best practices for them to improve their own programs. While no two programs look exactly alike, the Directors are unified in their heartfelt desire to improve the health and health care of the growing number of Americans who rely on the program.

Pharmaceutical coverage for children in foster care

Pharmaceutical coverage and expenditures have been a large and growing concern of the Medicaid Directors for a number of years. Psychotropics pose a unique concern primarily because the trends in costs and utilization are far outstripping every other baseline. Careful analysis of the data implies that this is a result of many factors, some legitimate, others less so. Concerns include both overutilization and inappropriate utilization, and this is true for adults, seniors, and, unfortunately, children as well.

As noted in the GAO report, this is also true, and especially concerning for one particularly vulnerable population, children in foster care. While psychotropic medications show enormous promise in treating a wide variety of serious conditions, there are clearly concerns about how current prescribing patterns can negatively impact the foster care population. The GAO report pointed out serious potential problems in three primary areas: the concomitant use of five or more psychotropics; prescribing doses higher than the maximum levels cited by FDA guidelines; and the prescribing of psychotropics to infants under 1 year old.

There is no question that subjecting our most vulnerable citizens to bad medicine is unacceptable and that we can and should and will do better by them.

But there is also no question that this problem is the result of a range of serious flaws in the US health care system: from the prescribing patterns of physicians to the lack of oversight of a variety of levels of government, the lack of effectively promulgated health information technology, and the fragmented nature of the relationship between acute care and behavioral health in this country. As such, solutions will require coordinated efforts from states, the federal government, mental health professionals, primary care practitioners, researchers, and others.

By definition, children in foster care are covered primarily by Medicaid, and, as noted in the report, “they tend to have more numerous and serious medical and mental health conditions than do other children.” While this does not excuse the delivery of substandard care, it does help to explain why psychotropic prescribing patterns for this population are higher than for the general population. We also note a recent study in the medical journal *Pediatrics* that shows that psychotropic prescribing patterns for children in foster care are even higher than those in the SSI population, who are by definition facing much more serious disabilities than the general population. This is likely true because many of the children who qualify for SSI do so because of physical, as opposed to behavioral/mental disabilities. To that extent, the foster care population may legitimately require more significant behavioral intervention than the overall SSI population.

There are other reasons to make sure we are making valid comparisons before drawing conclusions. In conversations with the medical and behavioral health experts in the states surveyed for the report, questions that warrant exploration were raised about the survey. For example, multiple prescriptions might reflect a prescriber legitimately cycling through a variety of potential medications in order to find the one that works best for an individual. Similarly, there are instances where multiple psychotropics may well be in the best medical and behavioral needs of a given individual. Further analysis of prescribing patterns for infants show that many examples are for Benadryl. This is not to excuse unacceptable behavior, or rationalize away serious problems where they exist, simply that more analysis is needed to figure out the nature and scope of the real underlying problems.

Challenges

There are unfortunately a number of reasons why state oversight policy, or medical practice may have failed to keep up with the ever changing literature or other developments. These are not meant to be excuses for failure to act, but indicative of the breadth of the challenges that face systemic reform. Furthermore, it cannot be stressed enough how unique are the challenges faced by the children in the foster care system.

While government has an obligation to lead, doing so in violation of clear community opposition is fraught with risk, and pyrrhic victories are often short lived. As states grapple with finding solutions to the epidemic of over- and misuse of psychotropics in general, they often face opposition from the manufacturers of these products, from mental health advocates (who in many cases are funded in large part by these same manufacturers), and from the community at large, who tend to resist government intrusion into a doctor-patient relationship often viewed as sacrosanct.

In some states, this has resulted in state legislative action that has placed absolute prohibitions on prior authorization of psychotropics like atypical antipsychotics. These laws place significant barriers on state pharmacy managers in their efforts to ensure compliance with the latest practice guidelines. While state legislative barriers are not permanently set in stone, resolving them does require different strategies than in addressing state-level executive branch policy.

These challenges also play out in the complicated relationship between state foster care workers, the children in the system, and the prescribers themselves. A lot of behavioral problems in foster care kids are as a result of trauma which is under-diagnosed and requires specialized treatment approaches.

As a practical matter, in an emergency, most prescribers are more likely to add medications than discontinue them, and effectively minimizing medication use requires a stable ongoing treatment relationship with a prescriber – a relationship that is rare, especially among older children who can change placements frequently, seeing a different prescriber each time.

State agencies also face challenges in recruiting and retaining sufficiently trained staff who possess the clinical expertise necessary to challenge a prescriber's recommendation to treat with psychotropics. One state in particular had to abandon an attempt to strengthen the hand of foster care workers in these situations, when it became clear that BA/BS or MSW educated workers would face significant liability issues when disagreeing with prescribers.

Solutions

In the short term, I would note that in my conversations with the states that were a part of the GAO study, all were undertaking efforts to address the identified shortcomings. I know that your staff have had extensive conversations with many, if not all, of these states, but we would be happy to continue to work with you if there is any further outstanding follow up required.

But above and beyond these individual efforts, there is also a need for broader systemic reform. There are a number of solutions that can and should be implemented to help improve this situation. 1) The GAO report recommends promulgating additional federal guidance from HHS to the states; 2) More clinical research is needed on the effects and implications of treating children of any age and in any situation with psychotropics that have only been tested on adults; 3) More work needs to be done to break down the barriers to coordinating and integrating care for vulnerable populations in Medicaid, with an added focus on the varied, complex and challenging behavioral health conditions experienced by children in foster care; 4) While Medicaid coverage and payment policy can and should change, many of the challenges in this issue are medical policy issues, and as such, require the broader medical community to also adapt; and 5) NAMD, working collaboratively with key partners such as the Medicaid Medical Directors and the State Mental Health Program Directors can develop and disseminate best practices in this area and work with states to implement them;

More HHS Guidance

While HHS has provided some guidance thus far, states would clearly welcome additional information. On behalf of our members, NAMD is committed to working with HHS, across the various agencies that impact this population, including the Administration on Children and Families (ACF) the Substance Abuse and Mental Health Services Administration (SAMHSA), the Center for Medicaid and CHIP Services (CMCS), and others. This is especially true in instances where state Medicaid agency policymakers need additional tools or leverage to convince policymakers in the state legislative branch or even state medical association leadership about changes to current policy.

The American Academy of Child and Adolescent Psychiatry (AACAP) guidelines contain four broad categories: consent, oversight, consultation, and information sharing. The preliminary investigation into the six sample states demonstrates a wide range of compliance with the non-binding recommendations in these four categories. We know that HHS is developing comprehensive guidance, and combining those recommendations with the power of transparency on this poorly-studied issue should help states improve their practices and improve the lives of foster children entrusted to our care.

Research on Psychotropic Impacts on Children

There are three major holes in the body of medical research relevant to this situation. The broadest is that there is not enough evidence on the comparative effectiveness of the various generations of psychotropics. FDA's mandate is to approve new pharmaceuticals based on performance relative to placebos, not relative to existing products.

A second relevant issue is the lack of understanding of how psychotropic drugs affect children in general. Children generally do not participate in FDA clinical trials for a variety of reasons, but there must be ways to work around this barrier to better understand how these powerful substances affect developing minds.

Finally, as noted in the GAO report, in an unspecified state, "57 percent of foster children were diagnosed with a mental disorder – nearly 15 times that of nonfoster children receiving Medicaid assistance." However, the report goes on to say that "very little research has been done on the use of psychotropic drugs in foster children with severe symptoms. This limits the information available to providers on how best to treat their conditions." The challenges faced by children that result in their placement in foster care combined with the challenges they face once in the system are nothing like those faced by either children in the general population, or even non-foster care children diagnosed with several mental illness. More work is needed to evaluate these unique challenges and to prepare for them.

Integrated and Coordinated Care

Care coordination— the alignment of treatments, various health professionals and regular care givers around a care plan for individuals with mental and physical health problems—is essential to good health outcomes and too often lacking in our nation's health care system. Further complicating good care, is the fragmentation between the fields of mental and physical health care. Privacy concerns, divergent

professional training, and splintered payment and coverage systems are just a few of the reasons why behavioral and physical health needs are thought of and addressed separately.

As noted in the GAO report, “foster children who change placements often do not have a consistent caretaker to plan treatment, offer consent, and provide oversight...changes in placement pose significant challenges for agencies, foster parents, and providers with regard to providing continuity of health care services and maintaining uninterrupted information on children’s medical needs and courses of treatment.” For them, the fragmentation between mental health and primary care is exacerbated by the transitory nature of their care and treatment regimen.

Medicaid, Medicare and private payers are actively investing in care coordination efforts, including medical homes, health IT and evidence-based medicine. These efforts should benefit foster children, but they are likely insufficient to address the range of problems without focused initiatives.

Medical Policy Changes

As stated by the AACAP, “the ultimate judgment regarding the care of a particular patient must be made by the clinician in light of all of the circumstances presented by the patient and his or her family, the diagnostic and treatment options available, and available resources.” Without disputing that assessment, it is clear that clinicians desperately need more information about not only the options available, but better data and analysis to determine their effectiveness and consequences. However, it is not enough to simply assume that more research will lead automatically and quickly to significant changes in practice. It is the medical professionals themselves, aided by their trade associations that must similarly commit to reforming how they practice medicine.

NAMD Best Practices

As I mentioned earlier, one of the two primary functions of our association is to help identify and disseminate best practices across all states. In this particular area, we have been and will continue to be strongly supportive of the efforts of groups like the Medicaid Medical Directors Learning Network (MMDLN) and the National Association of State Mental Health Program Directors (NASMHPD) to work with states to address these challenges. They have formed a consortium of 16 states representing about 12 million children and adolescents covered by Medicaid. Their work to date includes: analyses of each state’s antipsychotic medical use rates and trends for children, adolescents and those in foster care; the development of a set of safety, quality, or appropriate-use indicators to monitor treatment patterns; identification of state-specific programs and policies that could improve the use of antipsychotic medications; providing a forum for discussion of policies and programs for optimizing antipsychotic medication; and the development of a compendium of state practices that could be shared with other states to address issues related to antipsychotic use in children and adolescents.

This work resides on a public website and is already changing statewide practices across the country. With these tools states have the ability to work with prescribers to provide safer and more effective medication management across Medicaid or any population that chooses to use the guidelines.