# **UNDER THE MICROSCOPE**

**APRIL 1, 2012** 



# KEEPING AMERICA'S CHILDREN SAFE FROM ABUSES IN THE USE OF PSYCHOTROPIC DRUGS AND SECLUSION/RESTRAINT

#### TOPIC.

Those of us in the behavioral health and intellectual/developmental disabilities (I/DDs) fields, most child-serving adults, and virtually all parents work hard to keep the Nation's children safe. We work to ensure that young people with behavioral problems or I/DD have the services and supports they need to live in their communities and learn, grow and interact with others. And we work to ensure that, when necessary, children and adolescents have safe havens from abuse and neglect, such as through the foster care system, and that they have respite from severe symptoms of behavioral disorders through the limited, judicious use of psychotropic medications.

Today, however, some organizations designed to safeguard our children are getting failing grades in that effort. The foster care system, sometimes fails the children it should serve is by allowing children "in the system" to be unnecessarily medicated, often overmedicated, with psychotropic medications. Concomitantly, some schools and school-based programs designed to provide a safe learning environment for children with physical, mental and behavioral disabilities or disorders, are harming rather than helping. They fail when they inflict restraints and seclusion on their students and then compound the failure when they don't inform parents immediately.

The absence of specific federal and, often, state standards governing the use of restraints and seclusion in schools, and practices governing psychotropic drug prescribing for children and adolescents where parental consent is not available, such as foster care, are no excuse for these practices to continue. All of these practices not only are inappropriate, but also are dangerous, expensive and, at times, can be fatal. They are problems of national significance given the tremendous number of children and youth with behavioral disorders or I/DD; the just-released CDC report showing a sharp rise in the prevalence of autism spectrum disorders; and a recent Department of Education finding that seclusion and restraints are being used on tens of thousands of students nationwide. And it's an issue that demands local, community-based attention and action.

#### ANALYSIS.

# Who's affected...?

By <u>psychotropic drug prescribing</u>? Many children in foster care have experienced potentially emotionally and physically damaging traumatic life events. Some have experienced neglect and abuse; others been victims of or witnessed violence and trauma. Still others have parents with mental or substance use disorders. These and other vulnerabilities such as poverty, homelessness, and discrimination place them at increased risk for emotional problems and the introduction of psychotropic medications, often in great numbers and sizeable dosages.

The practice of prescribing psychotropic medications for children and youth has more than doubled over the last decade. Studies exploring the issue in a broad array of states confirmed that children on Medicaid and in foster care are at greater risk for receiving psychotropic medications than other children. While representing only 3% of children covered by Medicaid, children in foster care were prescribed antipsychotic medications at nearly 9 times the rate of other children on Medicaid. Data from individual states are telling:

- In Texas, children in foster care and on Medicaid were three times more likely than other children on Medicaid to get psychiatric medications; 40% were prescribed three or more separate psychotropic drugs.
- In Utah, over 35% of children in foster care with a diagnosed mental condition were on psychotropic medications.
- A Minnesota study found 43% of study-population children in foster care got some kind of psychotropic medication.
- In California, as many as 16% of children, ages 6-12, in foster care—that's elementary school-age children—were on psychotropic medications.

Moreover, the psychotropic drug armamentarium is being prescribed for disorders such as depression, ADHD, anxiety and conduct disorder among foster care children.

Significantly, many of these young people had not received a prior psychiatric assessment or diagnosis by a behavioral health specialist. Based on a 2-year analysis of the issue in five representative states, the Government Accountability Office told the US Senate last December that most monitoring programs fall far short of the best practice guidelines of the American Academy of Child and Adolescent Psychiatry, including its consent to medication guidelines. GAO noted that without regard to their potentially greater need for psychotherapeutic medication, foster children are being medicated largely in excess of medically recommended levels, with more medications than necessary, and at younger ages than safety requires. The report also highlighted an earlier finding that 34 of 48 states do not have programs in place to flag excessive dosages.

<u>By seclusion and restraint</u>? Seclusion and restraint are dangerous interventions that have led to trauma, injury and even death in children and adolescents. According to the US Department of Education, tens of thousands of students—from preschool through high school, report having been physically restrained or locked alone for hours. The term "student" is key: this practice is taking place in America's schools, a place that, in the ideal, is a safe place in which children can learn.

Critically, as many as 70% of children subjected to restraints or seclusion have disabilities of some kind. Some have diagnoses such as PTSD, ADHD or "a learning disability;" others have been diagnosed with autism, or I/DD. Children with these diagnoses do not automatically pose a danger to others; they are not invariably disruptive or aggressive. Yet they, above all other children, are subjected to restraint and seclusion.

The rationale for this potentially physically and psychological abusive behavior sometimes sounds altruistic: "saving a child from hurting him or herself," or "protecting students from harm." Some suggest that it's the only way to keep children with behavioral disorders or I/DD from being sent to residential institutions.

## What's wrong with these practices...?

Children in foster care often have been traumatized; the use of excessive psychoactive medications as an alternative, not a complement, to other one-on-one interventions may actually retraumatize them. Similarly, children with disabilities of any kind, particularly behavioral and I/DD —are at heightened risk for self-injury and suicide. Seclusion and restraint at school, at best, can traumatize and humiliate. At worst, it risks death, whether during its use or later, when the emotional repercussions don't heal.

While, psychotropic medications can reduce symptoms and restore functioning in adults, their effectiveness and safety have not been fully assessed and tested in children and youth. The ideal dosage, the optimal duration of use, and the ages at which medication is and is not indicated have not been established for either older or new-generation medications. Based on the limited knowledge base, short-term effects can range from sleepiness to significant weight gain and from tardive dyskinesia to suicidal ideation. Of even greater concern, some children are being medicated simultaneously with three or more psychoactive medications, often without a full behavioral assessment or diagnosis by a specialty provider. Again, the short- and long-term neurological and physiological effects on the growing body and brain are largely unknown—potentially dangerously so.

When it comes to restraints and seclusion, they're simply not good for anyone in a school environment, or most other environments for that matter. And they may not even be warranted in schools. According to a 2009 GAO report, on which the just-released Department of Education report builds, the vast majority of cases investigated involved children with disabilities who were not actively aggressive. Further, these practices may not have been legally sanctioned by family. In most case, parents had not given permission for restraint or seclusion and were not told about its use. Moreover, teachers and other staff generally have not been trained in the use of seclusion and restraints. And, perhaps most distressing of all, too many teachers and other staff whose

use of seclusion and restraint has led to students' deaths, continue in their role as educators in the same schools and often even the same classrooms.

How can these behaviors that can inflict such damage on our Nation's most vulnerable children continue? It's simple. Hospital use of seclusion and restraints is regulated by federal law; drug laws and research focus on adults, not children and youth. But no federal laws currently preclude either the use of seclusion and restraints in schools or the use of psychotropic medications in the treatment of children in foster care. State laws are a pastiche of good intentions and benign—or not-so-benign—neglect. Only 14 states limit the use of restraints to physical safety emergencies, and only 11 states either ban seclusion entirely or restrict it to physical safety emergencies.

# What's being done at the national level about these practices?

The good new is that efforts are underway through both legislation and regulation to help stem both of these unquestionably damaging, potentially lethal, practices.

As reported in the NACBHDD newsletter, legislation has been introduced in the U.S. House of Representatives by George Miller (D-CA) and in the US Senate by Tom Harkin (D-IA)—the "Keeping All Students Safe Act. Under the measure, schools no longer will be able to use seclusion and restraint to punish children or coerce compliance for non-dangerous behavioral infractions, or to use it in place of positive behavioral support or proper educational programs. The measure would ban mechanical and chemical restraints, and mandate same-day parental notification. Whether the measures become law remains an open question.

And late in 2011, Congress enacted the Child and Family Services Improvement and Innovation Act (signed into law by President Obama as PL 112-34), requiring states applying for federal child welfare grants to establish protocols for monitoring appropriate use of psychotropic drugs prescribed to foster children. Perhaps states might consider similar statutes making psychotropic drug prescribing a requirement for communities receiving state funding too.

Both efforts are a good start. And there is more.

The Department of Education continues to press states to develop or review/revise their state policies and guidelines to ensure that every student in every school under its jurisdiction is safe and protected from unnecessary or inappropriate seclusion or restraints. In 2010, the Agency promised to publish specific guidelines on school use of these practices, though, to date, it is unclear that final regulations have been forthcoming.

The Department of Health and Human Services has stepped in on psychotropic medication use among children in foster care, as well. The deliberations of an NIH workgroup studying the safety of atypical antipsychotics in pediatrics (of which Dr. Manderscheid was a member) gave rise to a "back box" warning about the potential dangers of the effects of one psychoactive, Olanzapine, on children and youth. It also made a series of specific research-focused recommendations that structure ways in which studies of the potential short- and long-term effects of mood stabilizers, antipsychotics and other psychoactive medications on children and adolescents can yield accurate, meaningful results that can safeguard lives. At the same time, ACF, CMS and SAMHSA are collaborating to educate and evaluate about psychotropic drug use in foster children. ACF will ask states to describe procedures and protocols that are in place to assure appropriate use of these medications. CMS is working with states to enhance drug utilization reviews and, with SAMHSA, is proposing the use of health homes as a means of improving the care of these at-risk young people.

## **ACTION STEPS.**

At the federal level, increasingly, valuable policy changes are taking place, but much also needs to be done in the trenches at the county level to curb these practices.

Take ten steps back for prevention. As reported in an earlier *Under the Microscope*, one of the best ways to achieve this goal is to move interventions upstream, to emphasize prevention. If the factors that can lead to behavioral difficulties—from abuse and trauma to poverty and homelessness—can be reduced, we can prevent the behavioral disorders that may lead to a school's misguided use of restraint and seclusion or the increasingly excessive use of psychotropic medications for children and youth in foster care settings. A number of models are doing just that today, among them:

- The Children's Resilience Initiative in Walla Walla, WA, which uses the ACES program to help reduce adverse childhood events that can lead to subsequent behavioral health programs; and
- The Kent County (MI) Prevention Initiative, which began investing in prevention and early intervention in 2000 to reduce the human and economic costs of adverse childhood events, such as abuse and neglect, substance use, family discord, criminal activity and illness.

Understand and educate about potential effects of psychoactives before prescribing. When it comes to the prescribing of psychoactive medications for children and youth, county behavioral health and I/DD experts can educate their colleagues in health care about the potential adverse effects these medications can have on children and youth, both in the short term, and in the longer term. You can emphasize the fact that prolonged use of second generation antipsychotic and mood stabilizing medications can lead to metabolic changes resulting in obesity and other negative effects in the short-term. In the long-term, these medications can actually increase a child's disability, reducing their ability capacity to cope with growing adversity, and ultimately reducing their life expectancy by decades. So, it's critical to educate your colleagues in the foster care system and non-specialist clinicians about the dangers of psychotropic drug prescribing for children and youth with behavioral problems or I/DD. Get the word out about best practices in this area; advocate for programs to better monitor psychotropic rug prescribing practices for use in children and adolescents.

Clarify that seclusion and restraint have no place in education. There is probably no occasion on which one would recommend the use of restraints or seclusion on school children of any age. That's why it's important to advocate for consistent laws and regulations across communities, states and the Nation to universally eliminate seclusion and restraints as a school-based practice. At the same time, collaborate with colleagues in schools, particularly for those working with children with special behavioral needs, about the dangers of seclusion and restraints. Get the word out about federal initiatives that are ongoing to end the practice—to save lives.

Link behavioral health to school-based health centers. New programs are underway at HRSA to bring health center into schools where they can provide prevention and early intervention services where the children are. Consistent with this concept of bringing the services to where those in need are found, county behavioral health and I/DD programs have a unique opportunity to link services together to better serve the needs of at-risk children and youth, joining health care to social services and supports, such as the foster care system. The integration of all aspects of health care right in schools, where at-risk children spend so much time, can help reduce the likelihood that there will be a need for seclusion and restraint, or for significant use of psychotropic medications among those in foster care.

When it comes to changing practices in programs serving our children and adolescents with behavioral disorders and I/DD, counties are ground zero. The opportunity to make significant change happen lies in your hands.

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