



STATE OF CONNECTICUT

OFFICE OF PROTECTION AND ADVOCACY FOR
PERSONS WITH DISABILITIES

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**Testimony of the Office of Protection and Advocacy for Persons with Disabilities
Before the Mental Health Services Working Group of the
Bipartisan Task Force on Gun Violence Prevention and Children's Safety**

Presented by: James D. McGaughey
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How did we miss him? I don't mean how did we fail to spot his potential for violence and then fail to prevent him from doing what he did. That would probably not have been possible: The news has been full of stories and letters and op-ed pieces quoting prominent psychiatrists and psychologists who are trying to explain that the ability of mental health professionals to predict violence is very limited, that the vast majority of people who live with mental illnesses have no tendency toward violence, and, indeed, that most mass killings are perpetrated by individuals who have no diagnosable mental illness. What I mean is: How did we miss the opportunities that must have existed to reach out and include him – to support him and his family in achieving a sense of belonging, of having a good and rightful place in the world and a positive vision for his future?

It would be irresponsible for me, as a public official, to speculate about this: I know nothing about Adam Lanza's personal history beyond what has been reported in the press, and my agency has not conducted any kind of investigation into the circumstances surrounding this tragedy. But it is a haunting question, especially for those of us who are advocates for people with disabilities. Because we know that despite the many programs and agencies that provide services, and despite the ever-advancing state of our knowledge about how to help people experiencing emotional distress, and despite the many wonderful examples of individuals with developmental disabilities and individuals with psychiatric disabilities who are achieving and contributing and leading good lives, far too many people and families are falling through the cracks; are stumbling over the gaps between and within service systems, find themselves having to do battle with insurance companies and managed care organizations, or having to wait for weeks and even months for appointments with clinicians. We know that far too many people struggling with mental illnesses or the types of developmental disabilities that have behavioral manifestations face rejection and marginalization and low expectations as school children, and, poverty, homelessness, inadequate healthcare, and outright discrimination as adults.

As you go about looking at how our state's responses to people with mental illness can be improved, I would urge you to begin by examining the experiences of families raising children who manifest signs of serious emotional distress, and the experiences of adults who live with mental illnesses. Too often program initiatives are born out of needs that are surfaced by providers or payers, not out of awareness of what would be helpful to primary consumers. We hear about kids stacking up in hospital Emergency Rooms, or adults winding up in jails and

prisons. So we launch programs narrowly tailored to address those problems. These are worthy goals, but they are half-measures. We need to look deeper and ask ourselves – and especially ask the people we want to help - what would this system look like if it was designed around the real needs of consumers from the bottom up.

Based on our Office's experience representing people through our Protection and Advocacy for Individuals with Mental Illness (PAIMI) program and our Protection and Advocacy for Individuals with Developmental Disabilities (PADD) program, I would offer the following thoughts on what we might change to make things better:

1. Support a comprehensive initiative to help school systems understand and fulfill their obligations to educate students who manifest signs of Emotional Disturbance and other disabilities that sometimes present behavioral issues.

Since the late 1960s, local education authorities in Connecticut have been expected to identify and educate students with disabilities, including students who present emotional and behavioral problems. Most of those students are (or should be) found eligible for special education and related services because the categories of disabilities that underlie their issues – Emotional Disability (ED), Specific Learning Disability (LD), Intellectual Disability (ID), Autism Spectrum Disorders (ASD), and Other Health Impairment (OHI) are specifically recognized in special education law, and because their disabilities are such that they interfere with the student's ability to benefit from the general education curriculum without an individually designed plan of modifications and supports. While these requirements are not new, however, most public schools remain ill-equipped to meet them, and the experience of families seeking appropriate education and relevant supports for their children is often characterized by painful struggle and bitter disappointment.

Historically, many of these students were sent to segregated "special" schools. However, driven partly by efforts to contain costs associated with the rapid increase in numbers of students manifesting both emotional and autism-related disabilities, and partly by growing recognition that, for many of those students, segregated schools were failing in their educational missions, local education systems have increasingly moved toward in-district placements. Theoretically, placement into one's local school alongside neighbors, friends and siblings is optimal: The student benefits from incidental learning that comes from association with non-disabled peers, gains a sense of positive identity as a full community member and emerges better equipped to deal with "real life". And, at the same time, the school community should be able to acquire competencies and develops resources that can benefit all its members. The problem is that after decades of relying on segregated placements, and facing enormous pressures to both contain costs and produce better educational outcomes, many local schools find themselves ill-equipped to deal with these students. In fact, many such students have been subjected to disciplinary exclusion or arrest, and many others have been left to flounder socially and academically - watched, but not well supported by teachers and administrators who just do not know what to do.

According to statistics generated by the State Department of Education, students identified with Emotional Disturbance labels (e.g. mental health-related disabilities) drop-out and fail to graduate from high school at alarmingly high rates. These students deserve a chance of a better future, but their school systems need help figuring out how to educate them, how to better coordinate with families and clinicians, and how to develop supportive, respectful, inclusive school climates. Bringing mental health services into schools could help, but if those services are relegated to “crisis intervention” tasks rather than being fully integrated into the school environment, little will change. What is needed is a more comprehensive approach – one that provides consultative resources with real expertise.

2. Expand the availability and scope of community-based, recovery-oriented mental health services.

The realization that people who experience serious mental illness can recover their lives – move beyond a diagnosis to work, have relationships, make contributions in their communities and the larger world – is leading Connecticut’s public mental health service system in a very positive direction. No longer are we content to simply manage symptoms, and, at the same time, attempt to manage people. But there are still enormous frustrations. Leaders really “get it”, but a lot of the system still hasn’t caught up with the recovery paradigm, and the resources needed to effect real, system-wide change haven’t materialized. Indeed, in many areas, accessing relevant services is still a tortuous process. Expanding the availability of genuinely recovery-oriented, community-based services would be one of the best investments this State could make.

In doing so, it is important to understand that mental health “treatment” is not synonymous with prescribing psychotropic medication, and “recovery” is not synonymous with a willingness to take them. The notion that people with psychiatric disabilities get into trouble if they are “off their meds” is an unfortunate oversimplification, and proposals to compel people to take medication are counterproductive. Often, people find themselves in difficulty because some other aspect of their lives has fallen apart – they have lost their home or job or an important relationship. While many people who experience mental illness do, indeed, benefit from psychiatric medications, the truth is that individuals vary considerably in their responses to these drugs, and in their susceptibility to side-effects, some of which can have serious consequences for one’s health. Not infrequently, people come to an informed decision about taking particular medication only after attempting various alternatives, including living without medications. Optimally, they are able to work with responsive psychiatrists and other treatment professionals as they discover what works best for them. This is especially important in the area of psychiatric medication because there are so few “biological markers” available to clinicians to assess the effectiveness of the drugs they are prescribing. They must rely on candid feedback from their patients, and they must give credence to that feedback. Too often, however, interactions with professionals are short, infrequent and insensitive to individuals’ concerns. This leads to a superficial

focus on things like “medication compliance” and formulaic approaches for “management of your illness/disease”, rather than on gaining a holistic understanding of the person and encouraging efforts to achieve genuine recovery.

Promoting recovery involves many types of supports and connections. People with psychiatric disabilities have the same fundamental human needs as everyone else: we all need a place to call home, food to eat, some kind of income, physical security, healthcare, meaningful work and opportunities to learn and contribute in the world. And, and we all very much need relationships with others. In fact, human beings are hard-wired to heal in relationships - relationships with friends, neighbors, family members and with peers who have been through similar experiences and can act as guides. Relationships with therapists and professional supporters can also be tremendously important for people who have lost their place in the world and are struggling to recover it. Yet those relationships can be irretrievably harmed, or never even develop in the first place if the person who is in need of help feels betrayed by those who are supposed to be helping. Unfortunately, the provisions of this Bill would encourage, and even legitimize practices that, from the perspective of the person struggling with a mental illness, would amount to such a betrayal. It is difficult to imagine how divulging confidential treatment information without the person’s permission, or setting up a situation where a conservator would be authorized to call in the police and ultimately employ force to administer medication could be anything but destructive to the type of trusting relationship that people need to have with their treatment providers.

Over the years, our Office has represented hundreds of people at hearings about “forced medication” in psychiatric hospitals. Often, hospitals feel pressured by insurance and managed care organizations to initiate medication quickly, short-circuiting essential processes of communications and relationship-building. Sometimes, people refuse to consent because they have had prior bad experiences with medications; sometimes they just need time to come to terms with their circumstances. I can attest that, amongst those who request hearings, much of the resistance to taking medication is rooted in a failure by others to listen to and credit their feelings and concerns. Nothing can produce resistance quicker than attempts to over-ride personal autonomy and force a person to take powerful, mind-altering drugs into their body. It is not an experience people soon forget. I seriously doubt that subjecting someone to court-ordered involuntary medication will result in insight, gratitude and ultimate success; it is more likely to produce resentment, further wounding and future avoidance of treatment.

Much of the alienation that so called “non-compliant” individuals demonstrate can be traced to one or more experiences where they were disrespected as human beings and subjected to some form of coerced “treatment”. Indeed, for decades, the blunt instruments of confinement, coercion and over-sedation were the principle tools relied on by our mental health system. We are now realizing that engaging people in treatment is a much more successful approach – one that leads to positive expectations and significantly higher levels of recovery. For treatment providers, acquiring the competencies necessary to genuinely engage people is critically important. That means, among other things,

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helping to empower people by forging real partnerships, instead of dis-empowering them by focusing on “compliance” and manipulating the legal levers of coercion. From a systems reform perspective, the goal is to develop treatment and support options that are viewed as relevant and trustworthy – ones that people will want to approach because they are affirming and useful; not ones they will seek to avoid because they worry that they will be subjected to judgmental, coercive practices. The last thing this reform effort needs is an invitation, written in statute, for those who provide services to seek judicial orders which disregard personal rights and actually expand the coercive options available to them.

In short, expanding access to relevant, recovery-oriented services would be an excellent investment, but venturing into the realm of court-ordered outpatient ‘treatment’ (a.k.a. forced medication) would be counterproductive.

Thank you for your attention. If there are any questions, I will try to answer them.