

The Moms' Mental Health Advocacy Group  
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VIA EMAIL AND USPS

Senator Dante Bartolomeo and  
Representative Diana Urban  
Legislative Office Building  
Hartford, CT 06106-1591

RE: Input on PA 13-178

Dear Senator Bartolomeo and Representative Urban:

This letter is in follow-up to our meeting on May 21, 2014 and in response to your request for our input on PA 13-178. As you may recall, we are a group of mothers who have children suffering with serious mental illness. For the most part we are middle class professionals in intact families with private health insurance. For many years, until the Newtown tragedy, we met for dinner once a month to share our stories with support, tears, and even humor. Most importantly, during these dinners we found a place where the stigma of mental illness was lifted and we could speak freely without judgment.

After Newtown, the Moms' Group decided to do more than simply support one another – we needed to become agents for changing problems in the mental health system, problems we have lived. We began meeting with state officials and with the media. We had the opportunity to appear on a *60 Minutes* segment that shed light on a very broken mental health system -- the segment was seen by more than 14 million viewers. We've written op-ed pieces and spoken at community events, including an Open Forum for the 13-178 Plan.

We are providing this document at your request, in order to prepare for upcoming meetings with DCF on the progress of the 13-178 Plan. The following comments and recommendations apply only to Section 1 and Section 6 of PA 13-178 since these are the areas in which we have had extensive experience.

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**Commercial Health Insurance:**

We have come to realize that we represent more than the families in our Moms' Group. In fact, the majority of the families in Connecticut, like ours, are covered by private health insurance. Since the majority of Connecticut's children are covered by commercial health insurance, it is critical that this sector of Connecticut's children is dealt with specifically in the 13-178 Plan.

It is likely that those responsible for creating the 13-178 Plan, including DCF and many of the Advisory Commission members, will view this issue through the lens of the agencies they represent, agencies funded by the state and created primarily to serve those with state insurance. The potential to overlook the population of children covered by commercial insurance is great, particularly since it is often assumed that those with private insurance receive more and better services. In our experience this is not necessarily true. And it is precisely because of this assumption and bias that the needs of children with commercial insurance must be specifically addressed in the Plan.

The rules and restrictions of our private insurance create significant barriers to obtaining care for our children in several ways:

1. **Limited Coverage.** Insurance carriers provide limited or no coverage for particular types of mental health services that are critical to treatment for some patients, such as in-home services. For critically ill children, it is essential to have all treatment options available so that the unique needs of the child may be met to create the best possible outcome. A disturbing reality lived by families dealing with mental illness is the disparity in treatment options for our children versus families of children with other medical problems such as cancer or diabetes. One can hardly imagine a situation where a child with diabetes or cancer would be denied a treatment option that could save or improve that child's life.

Yet we and our children experience this almost daily. Some examples: the child whose health insurance will pay for partial hospitalization but not intensive outpatient treatment or the reverse, clinicians forced to discharge children before they are ready or exaggerate symptoms to get that extra day or two of care covered; or the child who is in the hospital for two days, actively suicidal to the point of needing restraints but whose inpatient care somehow doesn't fit the insurance company's definition of "medically necessary" -- so the child is sent home; or the child whose family has to pay \$1,000 to \$2,000 for a neuropsychological evaluation because insurance won't cover it and the school district won't cover it, yet their child has never been fully assessed or properly diagnosed. Can you imagine treating a child for cancer without knowing what type or stage of cancer they have?

**Recommendation:** Require health insurance carriers operating in the State of Connecticut to work with mental health professionals to create a list of the full

range of services that are needed to adequately treat children and require that the carriers provide coverage for those services.

2. **“Not Medically Necessary.”** Our overwhelming experience is that the most frequent reason for a carrier to deny coverage is that the particular treatment is “not medically necessary,” even though it is the strong, unequivocal recommendation and plan of treatment from the child’s psychiatrist and the other mental health clinicians on the child’s treatment team.

The determination of “medical necessity” by the carrier feels arbitrary, since it is our understanding that at the initial coverage determination the personnel assigned to review the services often have no training in mental health. Those without specialized training in the complex field of mental illness cannot make a sound assessment.

Additionally, the term “medically necessary” is vague at best so parents are left feeling helpless and confused as to why coverage has been denied, delayed or changed. From our perspective, the term is often a set of standards that do not and frankly cannot, address the individualized and highly complex mental health issues with which our children are faced. One size does not fit all when you are treating a child with mental illness.

There is no question of medical necessity when the insurance company is presented with an x-ray of a broken leg or blood test results showing diabetes. There is no x-ray or blood test for most mental illnesses. There is a great deal of subjectivity with the treatment of mental illness, therefore the most informed course of action would be reliance on the prescribed plan of treatment developed by the child’s mental health providers. Instead the evidence and recommendations from the child’s clinicians are ignored and coverage is denied.

#### **Recommendations:**

- If the carrier requires prior or concurrent authorization, the personnel that review that service must be credentialed mental health professionals who are given the flexibility to make decisions about a child’s care without retaliation. Parents should be informed as to the reasons a child’s care is denied, delayed or changed and allowed input.
- Revise the “medical necessity” criteria so that it reflects a mental illness model. Include in the criteria a higher level of deference to the recommendations of the child’s psychiatrist and treatment team. For example, if the insurance company denies coverage in spite of the treatment team’s recommendations, the carrier should have a greater burden in defending its decision. Include in the criteria that the carrier must show that

it has taken the totality of the child's records into account in making its decision.

3. **Clinicians Not Accepting Private Insurance.** Many psychiatrists and therapists do not accept private insurance because the rates of reimbursement are too low and/or the hassles involved in working with an insurance company make it too burdensome for a provider to tolerate. This has multiple downstream impacts.

Obviously, if families must pay out-of-pocket for services, it means only those families that have disposable income will receive treatment, leaving an untold number of children without the care that they need. For instance, a psychiatrist prescribing medication can easily charge \$150 for a 15 minute visit to \$450 for more thorough assessment. A therapist/psychologist can charge \$100-\$250 per hour session and many children need to see them weekly. Most mentally ill children need to see both a psychiatrist for medication management and a therapist/psychologist for therapy. And it is not unusual for a family to have more than one child who struggles with mental illness. These medical visits, when combined with the cost of medication that these children typically need, result in monthly expenses that few can afford.

These families are in the untenable position of paying premiums for insurance coverage that they cannot use because there are not enough mental health providers that accept that insurance and they do not have enough disposable income to pay for services out-of-pocket. The result is that their children do not get the care they need.

Even for families who have resources to pay for services, the financial burden is significant. Some of our families have not only had enough expenses to take a deduction on their federal income tax which occurs only after a family spends 10% or more of their income on non-reimbursed medical expenses; others have considered divorce in order to decrease their household income and therefore qualify for state insurance. Many have exhausted college and retirement savings accounts, borrowed against homes and from family members, and literally bankrupted themselves in order to pay for the services to provide the care that is needed for their children.

**Recommendation:** Create incentives that would encourage mental health providers to accept commercial insurance. A successful incentive plan would have the twofold impact of creating access to people who have health insurance coverage but cannot afford to pay for services out of pocket and most importantly would make care available to sick children. Incentives could take the form of school loan forgiveness and/or tax incentives.

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**Prevention and Early Intervention:**

(addressed in PA 13-178 Section 1 (I) and Section 6)

Prevention and early intervention methods are transformational in the way they restructure the mental health system. Prevention programs bring mental health awareness into the lives of all members of the community through public education initiatives and dialogue.

We commend the legislature for passing a bill that would allow mental health or substance abuse treatment facilities to open satellite units or provider services at other locations without having to get a separate license. This is the type of program that will facilitate early intervention.

**Recommendations:**

- Expand the availability of mental health treatment in medical offices, education facilities and community organizations and incorporate comprehensive mental health screening as a routine wellness evaluation.
- Strengthen the capacity of professionals in youth and developmental programs to recognize risk factors and early signs of social-emotional problems and mental illness by the requirement of CPUs for school personnel and clinicians.
- Provide Mental Health First Aid training to parents and caregivers.
- Incorporate behavioral health screening, such as the Children's Depression Inventory, into routine physical exams. This self-assessment tool is used in children as young as 7 years old to identify potential areas of concern. Perhaps the schools can incorporate similar testing into their protocol at certain key points in the educational process. Currently our children are tested for scoliosis, why not mental illness?

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**Barriers to Access:**

Each of the more than 30 families represented by our Moms' Group has its own unique set of circumstances and experiences; however there are commonalities with regard to additional barriers to care that most of us have experienced:

1. **Lack of Knowledge about Available Resources.** Most of what we have learned about resources has been through our Moms' Group. This is not information that should be spread haphazardly by word of mouth. Our combined experience indicates that most clinicians are unaware of the range of resources that could be helpful (even essential) to their patients and their families. A mechanism must be created by which clinicians or others working with families educate the families

about the mobile crisis unit, Voluntary Services, how to find a DBT program, what IICAPS is, how the Green House can help your family . . . the list goes on and on.

**Recommendations:**

- A comprehensive clearinghouse for this type of information is a critical first step. We urge you to include the development of a data repository that includes patient/family feedback of community mental health providers and programs.
- Unfortunately, such a clearinghouse alone will be useless to many, if not most, parents. Believe us -- a parent whose child is suicidal or otherwise severely mentally ill is in no shape to successfully navigate even the most user-friendly clearinghouse. Therefore, a designated “care coordinator” role must be created and a care coordinator should be assigned to each family that has a child with a severe mental illness. The care coordinator would be a person who is familiar with the clearinghouse and with the family and has the responsibility for guiding the family to the resources that are appropriate and available. This comprehensive information database can then be used by care coordinators to create robust referrals appropriate to the specific needs of the patient/family.

2. **Additional Treatment Options.** (addressed in PA 13-178 Section 1 C – Comprehensive continuum of services.) Multiple treatment options and programs exist throughout the country. Connecticut could become the nation’s Center of Excellence by developing and implementing a statewide mental health care system that features the most effective treatments and programs.

**Recommendation:** Develop an office to review current research and programs focused on practical and innovative solutions with incentives for providers who are early adopters so that the new treatment modality gets into the community as soon as possible.

3. **Stigma.** (addressed in PA 13-178 Section 6 (7) ) There should be no shame in having a mental illness. Until we bring mental illness into the light and put a face on it, stigma will keep people with mental illness from seeking the care they need. Stigma keeps parents and siblings from reaching out to family, neighbors and friends for the support they so desperately need. People are starting to use the word “discrimination” instead of “stigma.” We couldn’t agree more. For example, a child with cut marks up and down their arms will be shunned, wear long sleeves all summer, and invoke fear in teachers, friends, neighbors, even family. A child with no hair due to chemo therapy will be embraced - as they should be - but so should the mentally ill child.

**Recommendations:**

- We trust that many of the PA 13-178 recommendations will include training for various professionals who are not clinicians, e.g., teachers, guidance

counselors, school administrators, boards of education, and pupil services personnel. We urge you to include in each such training session a meaningful presentation on stigma/discrimination. We would further urge that the presentation be given by a parent who has raised a child with mental illness and is willing to talk about the negative effects of discrimination and can help others understand their role in eliminating stigma. Including recovering teens and/or young adults who have lived or are living with mental illness would also be impactful.

- Mandate that units on mental illness and stigma/discrimination be included in the health curriculum at all grade levels -- elementary, middle and high school. Imagine the good it would do if children grow up with even a basic understanding of what mental illness is (and what it isn't). This past year, four students from Hall High School in West Hartford did a class project on the stigma of mental illness. They produced a powerful eight-minute video that will be used as part of Hall's tenth grade health curriculum. This could be used as a model. The link to this video is:  
<https://docs.google.com/file/d/0BzHz0YIYsRz5ay1qRmlGdl81YzA/edit>
- Incorporate the Institute of Living's "Stop the Stigma" campaign in training sessions, school programs, etc. There is something very concrete and powerful about having people sign an anti-stigma pledge and then as a group stand and tear up a piece of paper on which is printed words such as "psycho," "idiot" and "lunatic." The link to IOL's stigma campaign is:  
[www.StopTheStigmaCT.org/](http://www.StopTheStigmaCT.org/)

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### **Lack of Support from Our State's Child Welfare Agency.**

As far back as a 1999 Legislative Program Review and Investigations Committee Report, it was noted that DCF is not able to separate out its protective services orientation when dealing with Voluntary Services families. According to Commissioner Katz's legislative briefing of January 24, 2013, Voluntary Services is "designed for children and youth who have behavioral health needs and who are in need of services that they do not otherwise have access to." Yet, it is the experience of our Moms' Group that it is extremely difficult, and often impossible, to access appropriate services for our children through DCF.

1. **Lack of Flexibility.** Besides the child protection orientation of DCF, which is not appropriate for our families, DCF requires a family to fit into a prescribed process, which does not take the individual child into account or the child's experience with services that they have already obtained. Our group's experience is that our families have sought, obtained, and paid (frequently out of pocket) for all available community-based programs available to those of us with private insurance before seeking assistance from DCF. This typically includes evaluations and treatment from one or more of the following: psychiatrists, therapists, and

neuropsychologists; extensive outpatient individual, group, and family therapy; the mobile crisis unit; school evaluations and documentation of special education services; clinical day schools, emergency department visits and inpatient hospital stays.

Despite the fact that our families have taken full advantage of all community-based services that are available to us, when we have sought help from DCF for other solutions that we have not tried, DCF makes recommendations to begin again with yet another set of community-based providers. This harms our children by requiring them to endure more ineffective treatment and failures while their mental and emotional status erodes. By the time we approach DCF, we have spent years trying multiple community-based providers only to witness the steady deterioration of our children.

**Recommendation:** When we reach out to DCF for help we want them to treat us with respect and have the well-being of our children in the forefront of their mind, rather than adhering to a prescribed ideology that does not apply to each individual child. We want DCF to have the flexibility to meet our children where they and their experiences have brought them, rather than at the DCF prescribed starting point.

We urge you to require an IEP-type model which would take into account the needs of each specific child when developing treatment plans rather than making overarching policies to be applied to all children. The DCF system must be flexible enough to consider the needs of the individual child, treatments that were tried and failed, and then apply appropriate models suitable to the child, including coordinating not only with a child's parents but also with the psychiatrists and other clinicians who have worked with the child and may be making recommendations different from DCF's proposed solutions. At the risk of being redundant, would we treat every child with leukemia the same when there are a multitude of treatments available – some that work for some children and others that work for other children?

2. **Residential Treatment.** Insurance carriers often do not cover residential treatment or, if their policies include it as a covered service, they regularly determine that it is not medically necessary. Residential treatment is extremely expensive. Without financial help, residential treatment is outside of the reach of most families.

This has forced families to appeal to DCF Voluntary Services for assistance. Recently, DCF has made a policy shift that rejects almost all Voluntary Services placements out of the home and certainly out of state. Perhaps this policy is appropriate in the protective services context -- that is outside of the expertise of the Moms' Group. But in the context of Voluntary Services, this broad-brush, one-size-fits-all policy hurts the severely mentally ill children who need residential treatment, and it smacks of cost savings for the agency at the expense of the sick child.



Further, the current commissioner's policy edict that she must personally approve any residential, out of state placement is indefensible -- especially given the current commissioner's lack of professional training, credentials and experience in the highly-specialized area of the appropriate treatment of seriously mentally ill children and adolescents.

Most children with mental illness do not need residential treatment; however, for those children who do need it, it can mean the difference between a stable future and a future of revolving-door psychiatric hospitalizations.

**Recommendations:**

- In the context of Voluntary Services, reverse the policy that rejects -- as the starting point -- residential placements. The agency's policy should take as its starting point the considered recommendations of the psychiatrist and clinicians who have treated the child and who best know the child and the family. Honest flexibility must be built in to the system to allow for residential placements when they are warranted.
- In the past, Voluntary Services would assist a family who had a child who needed residential care (including out of state if an appropriate placement was not available in our very small state of Connecticut). DCF would assist the family with the cost of the residential portion of the placement on a sliding scale based on the family's financial resources. The current commissioner ended this type of assistance. We urge you to recommend that DCF return to that system.
- Clearly, in order to make an objective and informed determination of the need for residential care for a specific child, DCF needs to obtain an independent determination from a mental health professional -- it is harmful to the very sick children who need this intense level of care that these decisions are made by a person with no mental health treatment credentials.

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**Intersection of Schools and Mental Illness:**

Children spend most of their time in school. Therefore, it is imperative that schools are equipped to identify children that may have mental illness and have policies and procedures in place to handle these children in a developmentally appropriate and non-punitive manner.

Our experiences with school personnel include:

- Lack of recognition of the need for educational remediation or special education services. Children are often seen as having behavioral problems due to a lack of parenting skills.

- Teachers and other school personnel lack a basic understanding of mental illness and how it manifests in children. This leads to our children being disparaged by teachers in front of the class. The lack of understanding is so acute, that one family was asked by a teacher, “isn’t there an operation for that?”
- Since there is a lack of understanding of mental illness on the part of school personnel, there is also a lack of compassion and confidentiality. Rather than knowing how to deal with children with mental illness in the classroom, our children have been asked outright in the class, “Did you forget your meds today?” The ability of teachers to adapt lessons to meet the needs of students with mental illness, in our experience, is almost non-existent despite the fact that our children often have a mandated Individualized Education Plan (IEP.)
- For children who are seen by teachers and students as “different,” bullying becomes commonplace.
- Schools do not support conducting an assessment of the child even when it is indicated. We believe these decisions are largely driven by school budgets and town finances, not on the needs of the child. If a family has the resources to obtain an assessment on their own, it is common for the school to dismiss or diminish the findings and not provide the support indicated by the assessment. We know of one family who was told outright by the school that if the family had their own neuropsychiatric evaluation done, the school wouldn’t use it because they didn’t think it was needed. The parents did it anyway but have had to fight the school at every turn for appropriate accommodations.

**Recommendations:** We fully support the recommendations of the Task Force to Study the Provision of Behavioral Health Services for Young Adults, specifically recommendation numbers: 21-29 of the Final Report issued April 2014.

In addition, we recommend:

- Required licensure and continuing education credits for those directly teaching our youth should include advanced neurological research and how various students learn. For example, how does one teach a student who lacks executive functions?
- The IEP clearly needs to be tailored to the individual educational needs of the child and teachers need to be able to implement the plan. Training on adapting teaching styles and lessons is currently an enormous and critical gap that needs to be addressed.
- Identify strengths and talents of all students and integrate students with mental illness in all school projects and activities.

- Create a collaborative team approach so that school professionals work closely with pediatricians and mental health providers to provide the most effective and appropriate education.
- Assess classroom size so that if a teacher has five students with IEPs, for example, her/his classroom size should be significantly smaller than that of a teacher with only one student with an IEP or, if classroom sizes are the same, that the teacher with more students with IEPs have more classroom support. The same would apply to special resource room teachers. This number should be monitored and limited based on the degree of emotional, behavioral and educational support needed by the students assigned to the special resource teacher. Funds should be made available at the state (not town) level for these types of services.

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**Implementation of the Plan:**

PA 13-178 calls for “engaging communities, families and youths in the planning, delivery and evaluation of mental, emotional, and behavioral health care services.” (Section 1 (D)) Originally, 12 public forums were going to be held to obtain input to the plan, this was reduced to six. We have the following questions

- How will the information gathered at these public forums and in other venues be incorporated into the Plan?
- What mechanisms will be put into place to ensure that communities, families, and youths are contributing to the delivery and evaluation of services?

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We are grateful to both of you for taking the time to meet with us in person and for your invitation to provide input to the Plan that is being written to fulfill PA 13-178. We hope that this has been helpful. If you have any questions or if we can be of assistance in any way, please do not hesitate to contact us.

Sincerely,

On behalf of The Moms’ Mental Health Advocacy Group,



Nancy Aker



Mary Jo Andrews

*Beverly Brakeman*

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