Testimony in support of Proposed Senate Bill No. 119-An Act Establishing A Task Force To Study Hoarding

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Hoarding Issues from a Social /Mental Health Services Perspective

Hoarding is difficult to deal with from a Social Services perspective, first due to the resistance of people living with this diagnosis to come forward to request help. There is extreme shame and stigma attached to this diagnosis and studies have found it is a diagnosis that is most likely to alienate & antagonize family & friends. In two cases that we dealt with the person living with this diagnosis not only did not request help & or counseling but further ignored basic physical environment needs as they were too ashamed to have a repair person in their dwelling. In one situation the person went without heat for much of the winter & in another the person made the decision to store human waste rather than face the shame of having a plumber come in and see the conditions in the dwelling.

Additionally dealing with hoarding from a social services & mental health perspective is complicated by the fact that when someone finally seeks assistance or is identified & referred for assistance through other contact such as police, fire, ems, or repair workers there are very few resources to actually assist the person living with this diagnosis or condition. Financial resources are often limited and the cost of physically cleaning such a situation is exorbitant. Further it has been repeatedly shown that a simple cleanout does little to nothing to maintain the dwelling in that newly cleaned state & can make the hoarding even worse. This is a mental health diagnosis and without treatment has little chance of being rectified. Further there are insufficient treatment providers who specialize in treating hoarding.

Newington identified this as an issue that needed support and collaboration on a more global level including, state, municipal representatives, social service & mental health providers across the state. This was an issue that was larger than our single human Service department capacity. As such we reached out to CLASS- CT Local Administrators of Social Services and sent invitations out state wide to all emergency responders, legal, housing, insurance, & anybody working with hoarding cases to gather on this issue. We were amazed at the response. This was obviously an issue for all communities and people dealing with it are committed to seeking solutions as can be demonstrated by the more than 200 participants attending large meetings and subsequent subcommittees. We held a conference last year at CCSU which quickly filled (with a 330 person capacity). We are planning a second conference to be held this year on May 25th at CCSU and anticipate filling quickly again.

More education & awareness is needed. More financial resources and perhaps trained volunteers are needed to deal with the physical cleanout. More providers are need to provide quality mental health treatment to those living with this diagnosis. This is a multi- pronged problem that impacts all layers of the community, I implore you to recognize the scope of this issue and appoint a task force as was proposed last year in SB 18 and this year in SB 119.

I would additionally like to share comments forwarded to us from Blaise Worden PHD of Institute of Living, Anxiety Disorders Center

- Hoarding disorder (made a formal diagnosis in the DSM-5 in 2013) is probably the most common manifestation of hoarding behaviors, with past estimates at 2-5% of the population, and most recent estimates of prevalence at 1% of the population (Nordsletten et al., 2013). This is likely an underestimate, as hoarding typically goes undetected until severe. In addition to hoarding disorder, there are other problems which may be associated with hoarding behaviors/clutter, such as dementia/brain injury, depression, and schizophrenia. Ideal treatment for each of these issues is quite different and therefore assessment by psychological professionals with differential diagnosis is crucial.
- Hoarding disorder is a distinct mental health disorder, highly heritable, and rooted in neurobiological deficits (Woody, Kellman-McFarlane, Welsted, 2014). These neurobiological deficits include difficulties planning, problem solving, categorization, decision making, and sustained attention, making it extremely difficult for these patients to declutter, even if motivated to do so. Deficits of insight are common to the disorder as well, and in most cases are likely neurobiological and not "stubbornness." These are often titled executive functioning deficits—and are centralized in the frontal lobe. These cognitive deficits are similar to—but distinct from—deficits seen in ADHD.
- Cognitive-behavioral treatment is currently the most scientifically supported treatment for hoarding disorder, including all modalities (i.e., medications and psychosocial treatments). There is a great lack of providers statewide that are adequately trained in CBT, and only a handful that are knowledgeable about CBT for hoarding disorder. If patients live distant from Hartford, our clinic often finds we have no one to refer patients to, even when the patient desires treatment. Even sadder, we routinely encounter patients who for decades were unaware that an effective treatment was available.
- Psychologists generally are uneducated/unaware of the role of relevant service providers (e.g., fire, police, health dept. etc.) and when these services can intervene or assist. Our psychological practice generally encounters frustration when we contact social service agencies such as DCF or DSS about hoarding cases, as they are often unclear with us about when they can intervene and /or what the outcome was. We often find that reports made to DCF, DSS, or related services are not followed up on. We would love to communicate better with these agencies to create better continuity of care, and view this as a key benefit of the anticipated task force.
- The task force, in working together, can design more effective ways of risk reduction for the resident(s) and neighbors. Currently the nationwide emphasis is to use cleanouts which are extremely cost-ineffective. Without treatment, hoarding individuals are likely to return to baseline quickly after these cleanouts, which can cost municipalities tens of thousands of dollars.
- Individuals with hoarding are disproportionately high users of medical and mental health treatments. These individuals tend to have multiple medical and mental health diagnoses. Effective detection and referral to treatment has the potential to greatly lower social costs of medical and mental health care for these individuals.
- HD task forces are becoming increasingly common, with 75 communities implementing them as of 2010 (Bratiotis, Schmalish, & Stektee, 2011). While these task forces are effective, they tend not to stay active in large part due to absence of funding .