

## **CCHTF Meeting Minutes (Thursday June 30, 2016)**

### Introductions:

Members present at the meeting: *Erika Woods, BCDHE; Lois Carr, Bourne COA; Kathy Ganey, VNA of CC; Andrea Lavenets, Provincetown COA; Sherri McCullough; Brewster HD; Kathleen Pedini, Dennis COA; Carry Schoener, Dennis HD; Zackary Seabury, Orleans HD; Lynn Mulkeen, BCDHE; Melanie Bach, Pine Oaks Village; Linda Colby, Yarmouth COA; Lori Miranda, Dennis PD; Paul Wild, Elder Services of Cape Cod; Carol Bishop, Direct Services Provider; Kylee Sullivan, BUSPH*

### Erika's announcements:

- CCHTF support letter: described how the Task Force is attempting to garner community support for formalizing the CCHTF as a Barnstable County program to allow for funding and more services
- Disposal companies: Erika discussed and presented a document containing information about local disposal companies that can be used as a resource list to people with hoarding tendencies.
- CHNA 27 grant: Erika explained data findings from the direct services funded by the grant. She then went on to discuss the Buried in Treasures program. Topics discussed in this portion of the meeting include the following:
  - ADL (activities of daily life) had many challenges: it was not as easy to get information as previously hoped and the scale is extremely subjective; more training is needed with direct services providers ahead of time in future.
  - The CIR (clutter image rating) scale form was briefly discussed as well, however, its data results were not reviewed because the scale was not often used by the direct service providers
  - Erika mentioned that there was a 68% improvement in ADL scale values observed in the data collected from the grant. She said that this is a good starting point but collecting more data in the future is necessary for funding and services.
  - Grant details are as follows: the funding provided services to 17 people, of which the Task Force was able to get before and after data for 6 of those people.
  - Carol Bishop (one of the direct service providers from the grant) discussed how progress depended on how many services were able to be provided. Various limitations included motivation, encouragement, and lack of funding/time/resources
- Carol Bishop and Buried in Treasures (co-facilitated group a Buried in Treasures group in Provincetown): Carol discussed how there were 14 people in the group, with the program spanning 20 weeks, with 15 sessions and 2 hours per session. Participation in the group was not mandated, but rather voluntary. With that, there was a great turnout where 11 out of the 14 participants came every week.
- Main points of Carol's discussion are the following:

- Participants were committed to be there, which was great.
- No participant let anyone into their house until week 16 of the program.
- Feelings of trust and shame were a big emotional hurdle for the participants, especially with letting people into their house.
- This program also works as a therapy session; however, it is challenging to have a session that's therapeutic and productive in discarding belongings at the same time. Participants often were overwhelmed; they were skeptical of the help and who their information would be reported to. As a result, many participants were hesitant to allow pictures be taken of their home.
- Participants who were the most fearful wanted the most help and were the most desperate to improve their situation.
- Grant funding was supposed to provide each client with 4 hours of direct services (however, direct services did not end up being spread this way).
- The possibility of private payment in the future to make the program more successful was discussed
- Participant Demographics: age range of Provincetown participants was early 40's-74 (both men and women) but no one was in their 60's. About half of the participants were single.
- Hoarding is related to trauma and depression, as well as health issues (respiratory). Thus, hoarding is a health and safety hazard.
- Each participant knew they had a problem and could admit it.
- Even if a participant never put learning into action, they took the time to learn and were very committed. This created a tight-knit and supportive group.
- Linda Colby (Yarmouth COA): Linda discussed her experience with her first hoarder (who is also memory impaired). Linda got a coach to work with her client, which was going very well but now the client's daughter is visiting for the summer and is potentially hindering improvements for her mother. Linda asked the Task Force for advice on how to handle the daughter so that she does not negatively impact progress. Potential solutions discussed include:
  - Backing off of the client for summer while her daughter is visiting and expect to pick up in same spot after Labor Day while also doing wellness checks over the summer (suggested by Paul Wild).
  - The issue of whether the client may feel abandoned if Linda backs off for the summer was brought up. This is because Linda is "on the same team" as her client and so she may need the continued support and contact during the summer while her daughter is visiting.
  - Other topics discussed at this time include:
- A major issue is accumulation! People with hoarding tendencies often attempt to fill the void inside themselves by buying and acquiring new items. If accumulation stops, then the issue of what people with

these tendencies do with their time instead of accumulating was discussed (suggestions included going to the library to read or volunteering).

- The social aspect for acquiring is often the first major hurdle for most people
- Issues of funding coaches were discussed because coaches are so important but challenges arise with paying for one. Should funding come from out of pocket costs from the clients or should agencies help?
- The issue of changing group meeting times for Buried in Treasures groups was discussed and how this can disrupt progress made by participants.
- One strategy of changing the way people with hoarding tendencies think about their personal situation is to remove them from their house and show them pictures of it; once they are physically removed, people can finally see the mess/issue they have.
- The need for therapy along with cleaning sessions was discussed.
- Task Force members mentioned feeling frustrating with how quickly progress can be destroyed.
- Erika discussed the need for two parts – both the social work and organizational side, which was a major challenge for this grant. She mentioned that people don't want strangers in their home so it was helpful that many Provincetown Buried in Treasures people knew Carol before she entered their homes. Erika said how she hopes to keep this going forward, and how the Task Force will apply for more grants in the near future. If the Task Force becomes a county program it will have more resources. Also, she mentioned how there needs to be further research into the health insurance portion of this issue because hoarding is now considered a mental illness in the DSM V.
- The need for Buried in Treasure books for newly forming Yarmouth Buried in Treasures group was discussed.
- Tabletop exercise: the difference between Hoarding and Squalor was discussed.
- Sanitation issues are a part of squalor, which often times is focused on more than the issue of hoarding and hoarding initiatives are lost. The two conditions are completely different situations and require different responses. However, the difference can be hard to determine because there is a struggle for subjectivity.
- Hoarding is defined as being unable to discard belongings, resulting in the inability to use space for its intended use (a mental health issue).
- Squalor is defined as a sanitation issue, often involving filth, rotting food, flies, rats, etc.
- Hoarding can lead to cases of squalor when the inability to use space for its intended use creates sanitation issues.
- There is a lack of research on this topic making it challenging to study. However, knowledge needs to be available in an attempt to minimize subjectivity.

- A picture exercise to determine hoarding v. squalor situations was conducted. This led to a discussion of the CIR scale and what the scale means. The CIR scale is subjective but it is still a good tool to use. The idea of using the scale as a motivational tool to encourage clients to get to a certain number on the scale was discussed. However, a conflicting point was brought up; often times what a therapist sees versus what the client sees in terms of degree of clutter is different. Conveniently, the CIR scale is available as an app on iTunes when assessing clients' home.
- Dennis Health Department (Carry Schoener) brought up an issue they are having: how do you gain access and trust from these residents while being an enforcing agent?
- It was mentioned that the title of a Health Department employee who enforces codes works against the ability to help people with hoarding tendencies. Clients have the right to refuse you access to their homes. Residents are embarrassed and upset because they are targeted as hoarders by neighbors. The idea of bringing a representative from the fire department or someone else with you when going to these residents' houses to mitigate hostilities due to the Health Department's enforcing nature. Bringing fire alarms or something like that may be helpful (to make it more of a wellness check).
- A lot of departments look to Health Departments to handle the issue of hoarding, however, Health Departments can only issue an order and tell residents to clean their property. This can become a legal issue.
- The idea of creating a Dennis-specific group to address the issue of enforcing code and helping residents was discussed. Uniting different departments within the town to create a model of how to approach this issue was suggested.
- Replicating the Boston program in Barnstable County was discussed. Boston has been very effective with a 98% success rate and no hoarding-related convictions since the program's implementation.
- Program initiated by the MBHP (Metropolitan Boston Housing Partnership) and it has a lot of funding.