Collaborative Support Programs of New Jersey
Position Paper
System Reliance on Boarding Homes, Rooming Houses, and RHCFs

Collaborative Support Programs of New Jersey (CSPNJ), originally known as Collaborative Association of Support Programs (CASP), began in Asbury Park in the early 1980s. A group of people that included clergy, former or current recipients of mental health services, volunteers, and mental health professionals joined together to provide supports to people living with mental illness who were residing in boarding homes in the Asbury Park and the surrounding shore area. Members of CASP shared the belief that boarding homes and Residential Healthcare Facilities (RHCFs) were for the most part not decent places for people with special needs to reside within the community. This position paper outlines multiple reasons as to why the homes and RHCFs are not appropriate places to live for those with the lived experience of mental illness.

The reasons why CASP felt this way included many factors:

- Poor environments
  - Dilapidated buildings that were not kept up to code or were unsuitable for inhabitants
  - Inadequate furnishings
  - Lack of adequate heat and/or air conditioning[1]
- Lack of privacy
  - Usually two or more people to a bedroom
- Inadequate supports
  - Little or no support services
  - Poorly trained staff, with no specific mental health training
  - Few or no regular linkages between the residential settings and mental health care or community nursing services
- Poor nutrition.
  - Unhealthy meals; often very high in fats and simple carbohydrates[2].
  - Few choices.
  - Few or no accommodations for diets based on medical needs or religious guidelines.
- Stigma residents experience as a result of numerous disabled, impoverished people being grouped together
- Arbitrary rules set forth by operators
- Little control of and lack of funds causing
  - Begging
  - Theft

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[1] This last was an especially big hardship on many people on significant doses of antipsychotic medications. The medications impair a person's ability to tolerate heat, and we have had experiences in NJ and elsewhere of people using these meds dying in inadequately ventilated rooms during summer heat waves.

[2] Another very unhealthy combination, this time with the high rates of middle-body obesity and diabetes among people using antipsychotic medications

- Crime, including incidents of
  - resident-on-resident violence and other crime
  - victimization by community members, especially in high-crime areas
- Segregation from society
- Limited medical care. Some facilities licensed as "Residential Healthcare Facilities," average 11 minutes of nursing time per resident per week. Relatively healthy patients may see a nurse for nothing more than a quarterly re-assessment.
- Pressure, often exerted illegally, to use mental health day treatment programs with very limited rehabilitative value
- High rate of return to psychiatric inpatient facilities.

CASP took a stand that these congregate living situations should not be proliferated, that many should be closed, and that alternative housing and support should be arranged and developed. Several years later, CSPNJ assisted in initiating the supportive housing movement in New Jersey as an alternative to this type of living arrangement where people are treated as tenants in their own homes (or small shared living setting) with a range of supports and a housing subsidy. Over time, the Division of Mental Health Services (DMHS) became very involved in supportive community housing. As a result, boarding homes became options of last resort for people being discharged from state psychiatric facilities. Many people being discharged from state hospitals today find themselves in much smaller congregate living settings operated under DMHS contract by local agencies. They still may lack privacy and have less autonomy, and often find themselves pressured into using non-rehabilitative services such as day treatment or sheltered work, but there is usually a higher level of support, better integration with the community continuum of mental health services, far better care of facilities and furnishings, better attention paid to nutrition and medical care, and at least nominal planning for moving people out of these settings to real community living.

Twenty years later, while there are fewer of these congregate living homes, there are still too many recipients of mental health services residing in large group living settings throughout New Jersey. Residents are still receiving poor supports, and all of the factors discussed above remain relevant. Boarding homes remain an option for individuals who are ready to be discharged from hospital settings or who have been unsuccessful in more independent settings. Often, especially in the larger and more institutional boarding homes, living conditions are not conducive to supporting mental health recovery. Placing people in deplorable environments and subjecting them to the social and emotional strains of unstructured and unsupervised congregate living is not a good plan.

The conditions in most of these facilities remain inferior to the vision of the wellness and recovery model that we have now embraced. The many problems at one particular RHCF located in Ocean County are representative of the industry. The problems include violence (often continuous police calls), community harassment, residents being killed walking across the highway (you must cross one of the busier roads in the county to get to a store), a lack of dignity for residents, and a tremendous amount of stigma with ongoing news articles and town protests concerning the facility's inadequate care. Many facilities are poorly located, with no consideration as to the impact that their location has on a population of residents who

have limited transportation because of their inability to afford a car or because they cannot obtain a driver's license due to the medication they are prescribed. Some facilities are miles from the nearest store, public transportation route, house of worship, etc.

The following are comments from people who have lived in these settings:

"A guy stuck a knife in both my ears while I was asleep in bed. I was very scared. This attack left me with a bad hearing loss in both ears. I finally got two hearing aids so I can hear again. It must have cost Medicaid a lot of money. There was an investigation. I don't think they ever caught the guy."

"We were sleeping in our room and I woke up to find a fellow resident creeping up my roommate's bed whispering shh, you'll enjoy it'.....I got out of bed and he tried to talk his way out of it but I called the boarding house owner and he was arrested. I went to see my case manager the next day and asked him to get me the h-___out of there. We never felt secure in that place."

"One night this male resident was discharged for drinking on the premises. He walked thorough the woods late that evening and entered our boarding home through the back door to see his girlfriend. He was of an artistic temperament and with his utility knife cut his body all over with this knife. The whole room looked like a slaughter house before he was finished. We were horrified. As I recall, this incident hit the papers because it was so awful."

"*I've stayed in three boarding homes recently....my experience was very degrading....there was very little food served, one sandwich at lunch with very little filling, a glass of kool aide or lemonade, never any healthy drinks. We did not have any choices in our meals, and there was never any second helpings. For a six foot man, it just wasn't enough. The other residents were always hungry. We could not go to the kitchen after dinner for any snacks or drinks."*

"We had to stand in line at 7:00 am with our toiletry items to get ready for program with only one bathroom for seven people. One place was so dirty and run down, it had 68 people living there. One guy got punched in the face while he was in bed. I never felt safe and begged my mother to get me out of there. There was no air conditioner and I had to pay extra money to get a bed with a fan. I had to go to my room after dinner. There was not a common area where we could sit. In the morning, I like to have a cup of coffee with my cigarette but I wasn't allowed to take the coffee on the porch. It seemed I was always following rules, never a choice, no dignity, just a number."

"The boarding home industry was seen for the boarding home operator to make a quick dollar, giving little services to its residents, and situated in areas far away from public transportation and community shops and churches. Residents were forced to stay in line to eat their meals, forced to sit in specific seats at mealtimes, and were given medication by either the cook or a consumer "manager." These boarding homes had no connection to the community; I had to be home by 10:00 p.m., or get locked out of the home until morning.

Unfortunately for me, and hundreds of consumers, the cost of other expenses, such as laundry, was not included in the rent. I had one dresser with four shelves, shared a bathroom with a shower, and a tiny closet that held only two or three suits."

"There was no access to a telephone, and at times, I saw the boarding home operator opening the personal mail of the residents. When I was in the hospital, three of my father's rings were stolen. They were all expensive. They were all given to me by my mother. My boarding home operator said that I was confused. I assured her that I was not confused. She threatened me with eviction if I did not go to the program. She was extremely cruel to people that she didn't like, and evicted them."

CSPNJ, through our Self-help Centers has been providing outreach to congregate living facilities for several years. We continue to feel strongly that these types of living facilities are not conducive to mental health recovery and wellness. We believe that New Jersey needs to begin the process of significantly limiting the use of boarding homes and RHCFs for people with serious mental illness who are being discharged from psychiatric hospitals. Only in cases where a person makes a clear choice to reside in this type of congregate housing should it be considered, and only if the state provides the necessary supports.

A few boarding homes and RHCF's have shown that residents can be provided a safe environment with adequate, if not good care, in a small congregate setting for those individuals who need a greater level of support than can be provided in a supported housing environment. These facilities should be the model for the industry and be held as the gold standard for all others to aspire. If the state intends to continue to use these facilities as a means of housing individuals with mental illness, they need to be monitored and licensed by the Division of Mental Health Services as would any other residential program in which mental health consumers are living.

While we are aware of the significant budgetary crisis facing the State of New Jersey, the costs of placing people being discharged from psychiatric hospitals in these facilities with inadequate care and support is not economical. It may seem less expensive in the short term to place people in these places, but the long-term costs of continual re-hospitalization and lost lives in terms of mortality, morbidity, and quality of life are staggering.

The Federal Court's Olmstead decision mandated that people with disabilities be given the opportunity to reside in the least restrictive environment possible. These facilities do not meet these criteria for most people. Thus far, too many people are being "placed" inappropriately in these settings as a means to meet the mandate. The mental health system should not depend on these facilities to warehouse the most vulnerable of our peers. In addition, this can be a false economy – as these non-recovery oriented systems keep people dependent on treatment and services, rather than leaving day treatment, moving on to work, and reducing their reliance on expensive medications.

In New York City, the courts have become involved in attempting to reduce the number and size of these places. The decision by Judge Nicholas Garaufis of Federal District Court in Brooklyn stated that conditions at these privately run homes in NYC violated the American with Disabilities Act by leaving residents isolated from the outside world in warehouse-like conditions.

We believe that the communities' negative views of people living with mental illness are exacerbated by the negative living environments of most boarding homes. Residents often wander the streets because they are told not to stay in the homes during the day or because the environments are so toxic that they prefer to be out most of the time. These facilities become psychiatric ghettos that are not good for the individuals or for the local community.

We support the following:

- Verifiable offers of a continuum of housing as part of discharge planning at the state psychiatric hospitals.
- The development of additional housing slots in the community for transitioning those who are willing to move.
- Setting aside state funding to assist people in moving to places and areas they prefer.
- Vouchers to subsidize rents.
- A commitment by the state legislature to take this issue on and to instruct the state bureaucracies involved to build upon successful models of support that recipients of mental health care want and do well in.

Collaborative Support Programs of New Jersey (CSPNJ) will be submitting periodic position papers on topics we believe are important to peers throughout the state. This paper, our initial one concerns "Systems' Reliance on Boarding Homes, Rooming Houses, and RHCFs." CSPNJ began in Asbury Park as a faith-based organization that advocated for better treatment for persons diagnosed with serious mental illness in the community. Our focus has been and remains advocacy for improved treatment for people with a mental health diagnosis. People who have no other alternative than to live in unsafe environments that lack supportive services often find themselves at a dead end of poverty, isolation and victimization. Placing vulnerable persons in these situations does not make sense in a recovery oriented system of support.

These are difficult times; and the state and nation are experiencing profound financial hardship. It is costly to continue to expand the housing choices for those awaiting discharge, but is also expensive for people to be repeatedly readmitted to hospitals costing the taxpayers more than $400 per patient day because their living environment was not conducive to recovery. Upon discharge, we realize that most people often choose to leave the hospital as soon as possible and move anywhere just to be in the community. We cannot continue to rely on outdated congregate group living environments that are detrimental to people's quality of life as well as their ability to become successful and productive community members. The New Jersey mental health system needs to expand and enhance what we already have and limit the use of components that offer inadequate supports and environments.