

Helping Tennessee's Supportive Living Facilities Offer Board and Care for All

A White Paper on the Conditions Found in Supportive Living Facilities Across Tennessee



Disability Law & Advocacy Center of Tennessee
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The following report is presented to address unacceptable operating practices of licensed board and care homes (supportive living facilities) for persons with mental illness in Tennessee. Issues and recommended solutions found within are drawn from numerous monitoring visits, policy reviews, and dialogue with residents and owners/operators. The current lack of compliance with licensure rules and oversight create a risk of potentially dangerous consequences for some of Tennessee's most vulnerable citizens – persons with mental illness residing in board and care homes. Occurrences of physical and emotional abuse, neglect, and financial exploitation may remain undetected due to inadequate supervision and monitoring and failure to take action when compliance is lacking.

Residents may feel disempowered to change these situations or self advocate under such circumstances. Many lack the ability to protect themselves while others believe that they have no choices or options. All too often, residents' only alternatives to board and care homes include institutions, hospitals, shelters, jails, prisons, and even homelessness. Limited financial resources, lack of supportive family, few safe alternative living arrangements, and insufficient community resources frequently result in helplessness and passivity.

In order to protect board and care home residents, Tennessee must stop ignoring the risk of abuse and neglect faced by residents simply due to living in board and care homes, address the flagrant lack of compliance with licensure rules, effectively monitor these facilities, and take corrective action when non-compliance occurs. Many of the proposed actions in this report should be taken immediately. The Tennessee Department of Mental Health is ultimately responsible for the development and implementation of safe and appropriate housing programs for persons with mental illness. Collaboration with stakeholders, including the licensure board, mental health advocates and providers, family members, and most importantly, persons with mental illness, will result in supportive living facilities that provide quality board and care for residents.



Barbara Simmons
PAIMI Advisory Council, Chairperson



Shirley Shea
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EXECUTIVE SUMMARY

Disability Law & Advocacy Center of Tennessee (DLAC) is the State of Tennessee's designated protection and advocacy system. DLAC is federally mandated to protect and advocate for the rights of persons with disabilities including those who reside in supportive living facilities/board and care homes. In keeping with its authority, DLAC investigates allegations of abuse and neglect and monitors facilities to ensure protection from harm, neglect, and financial exploitation as well as to ensure a high quality of available services for persons with disabilities.

Currently, supportive living facilities for persons with mental illness and persons with intellectual disabilities are licensed by the Tennessee Department of Mental Health (TDMH). Supportive living facilities are known as supportive living homes, group homes, boarding homes, or board and care homes in their respective Tennessee communities. Throughout this report, licensed supportive living facilities are referred to by their most commonly used name "board and care homes."

This document sets forth information gathered by DLAC investigators during monitoring visits to 60 board and care homes across Tennessee during 2010. Thirty (30) of the homes served persons with intellectual disabilities; 30 homes served persons with mental illness. DLAC documented a notable difference between licensed homes for persons with intellectual disabilities and those for persons with mental illness.

To reconcile this inconsistency, DLAC challenges TDMH to replicate the licensure rules for housing for residents with intellectual disabilities and apply those same rules to housing for residents with mental illness. Persons with intellectual disabilities and persons with severe persistent mental illness are particularly vulnerable to harm. It is thus advisable to have similar rules for all homes licensed by the State. DLAC is confident that implementation of these recommendations will provide the conditions necessary for persons with mental illness to reside in safe environments and be more autonomous in their living arrangements.

SCOPE OF PROBLEM

Mental illness is the leading cause of disability in the United States.

Board and care homes are a link in the process known as deinstitutionalization. Deinstitutionalization refers to the policy of moving people with severe disabilities, including intellectual and other developmental disabilities as well as mental illness, out of large state institutions and public hospitals and closing part or all of those institutions. As a result of deinstitutionalization policy, the goal of community integration for those who have intellectual or/other developmental disabilities or diagnoses of serious mental illness has become increasingly important.¹

Developmental disabilities are defined by the Centers for Disease Control as

“a diverse group of severe chronic conditions that are due to mental and/or physical impairments. People with developmental disabilities have problems with major life activities such as language, mobility, learning, self-help, and independent living. Developmental disabilities begin anytime during [child] development up to 22 years of age and usually last throughout a person’s lifetime.”²

Developmental disabilities include intellectual disabilities.

Mental illness is the leading cause of disability in the United States.³ One in four adults—approximately 57.7 million Americans—experience a mental health disorder

1 Mowbray, C. and Holter, M. 2002. “Mental Health and Mental Illness: Out of the Closet.” Social Service Review (March 2002): 135-179

2 “Developmental disabilities” (2011). Available at <http://www.cdc.gov/ncbddd/dd/dd1.htm>

3 “Leading Categories of Diseases/Disorders” (2011). Available at http://nimh.nih.gov/statistics/2LEAD_CAT.shtml

in a given year. One in 17 adults live with a serious mental illness such as schizophrenia, major depression or bipolar disorder.⁴ The economic impact of mental illness in indirect costs each year is estimated to be \$79 billion. Most of that amount reflects the loss of productivity as a result of illnesses.⁵ Diagnoses can include but are not limited to schizophrenia, bipolar disorder, major depressive disorder and post traumatic stress disorder (PTSD). Twice as many Americans live with schizophrenia as with HIV/AIDS. Nearly half (45 percent) of those with any mental illness meet criteria for 2 or more diagnoses.⁶ There may be one diagnosable occurrence or several that can develop at any time in a person's life.

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The vast majority of persons with mental illness are able to live productive lives with no supports or services or with minimal assistance from mental health professionals. Even though mental illness is widespread in the population, the main burden of illness is concentrated in a much smaller proportion — about 6 percent, or 1 in 17 — who live with a severe and persistent mental illness.⁷ Persons with severe and persistent mental illness often require extensive supports which may include utilizing board and care homes when transitioning from inpatient therapeutic settings or long-term residency within board and care homes. DLAC investigators focused on board and care homes for persons with severe mental illness who need supports/services in order to live in the community.

4 "NIMH: The numbers count—Mental disorders in America." National Institute of Health. Available at <http://www.nimh.nih.gov/publicat/numbers.cfm>

5 U. S. Department of Health and Human Services. Mental Health: A Report of the Surgeon General. Rockville, MD., U.S. Department of Health and Human Services, Substance Abuse and Mental Health Services Administration, Center for Mental Health Services, 1999, pp. 408-409, 411

6 "NIMH: The numbers count-Mental Health disorders in America." National Institute of Health. Available at www.nimh.nih.gov/publicat/numbers.cfm

7 "NIMH: The numbers count-Mental Health disorders in America." National Institute of Health. Available at www.nimh.nih.gov/publicat/numbers.cfm

Deinstitutionalization is based on the principle that severe disabilities should be treated in the least restrictive setting.⁸ This practice began in 1955 with the introduction of the first effective antipsychotic medications. Until that time persons with mental illness were often warehoused in isolated areas of larger hospitals and received minimal treatment.



It is now widely accepted that most, if not all, people with severe disabilities including mental illness can receive more effective treatment in small, supervised group homes than in institutions. Today, there are a range of residential treatment programs available. For those patients needing the most supervision, there are residences that are fully supervised with trained staff members present 24 hours a day. Those able to live more independently live in apartments where they are visited by mental health workers as often as their condition warrants. In Tennessee, a significant number of people with severe mental illness live in board and care homes licensed by TDMH.

8 Torrey, E. Fuller (1997): *Out of the Shadows: Confronting America's Mental Illness Crisis*. New York, NY: John Wiley

EXISTING CONDITIONS

Many issues represent an alarming potential for harm, including abuse, neglect, and financial exploitation.

Currently, residents in board and care homes are not being provided the best level of care. DLAC investigators conducted monitoring visits to 60 board and care homes throughout the three grand divisions of Tennessee, visiting facilities for persons with mental illness and those for persons with intellectual disabilities. Each facility held a current license issued by TDMH. Though DLAC's investigation focused on facilities licensed to serve both populations, investigators ultimately concluded that concerns were greater in the board and care homes that serve persons with mental illness. Thus, the issues identified in those facilities became the focus of this report.

Overall, the provision of services in board and care homes was found to be an illusion with many issues representing an alarming potential for harm, including abuse, neglect, and financial exploitation. During DLAC's monitoring visits, investigators observed that persons with mental illness (residents) living in board and care homes experience poor living conditions, lack of oversight, and greater opportunities for exploitation. Issues identified by DLAC investigators are categorized under the areas of administrative practices; health and safety; and self-advocacy.

ADMINISTRATIVE PRACTICES

- **Lack of Policies and Procedures** – Upon request, owners/operators were not consistently able to provide investigators with any written policies or procedures addressing facility services, fee schedules, client confidentiality, safety procedures, or the reporting and investigation of suspected or alleged incidents of abuse and/or neglect. This violates *Rules of Department of Mental Health and Developmental Disabilities Office of Licensure Chapters 0940-5-4-.06, 0940-5-6-.02, 0940-5-19-.01.*
- **Lack of Client Records** – Upon request, owners/operators were not consistently able to provide investigators with appropriate client documentation, including client demographics, emergency contacts, client's diagnosis, and signed consent

and authorization forms. This violates *Rules of Department of Mental Health and Developmental Disabilities Office of Licensure Chapters 0940-5-6-.05, 0940-5-19-.04.*

- **Personnel Issues** – Upon request, owners/operators were not consistently able to provide investigators with verification of staff training/development, personnel records including job description, and evidence of adequate supervision. This violates *Rules of Department of Mental Health and Developmental Disabilities Office of Licensure Chapters 0940-5-6-.04, 0940-5-19-.02.*

CASE IN POINT

ONE INVESTIGATOR REPORTED VISITING A FACILITY WHERE THE OWNER/OPERATOR WAS OUT OF THE COUNTRY FOR 30 DAYS AND DID NOT MAKE PROVISIONS FOR ADEQUATE SUPERVISION OF THE FACILITY. IN THIS INSTANCE, ALTHOUGH A NEIGHBOR PERIODICALLY CHECKED IN ON THE RESIDENTS, NO STAFF MEMBER WAS PRESENT IN THE FACILITY 24 HOURS A DAY AS SET FORTH IN THE RULES.

HEALTH AND SAFETY

- **Lack of Adequate Documentation Regarding Nutrition** – Upon request, owners/operators were not consistently able to provide investigators with any written records of food intake. This violates *Rules of Department of Mental Health and Developmental Disabilities Office of Licensure Chapter 0940-5-5-.05.*
- **Lack of Sufficient Medication Oversight** – Upon request, owners/operators were not consistently able to provide investigators with a copy of the facility's medication administration policy. This violates *Rules of Department of Mental Health and Developmental Disabilities Office of Licensure Chapters 0940-5-6-.02, 0940-05-19-.06.* Staff authorized to administer medication to residents disclosed having received no medication training. Additionally, facilities were unable to provide proof of MARS (Medication Administration Record Sheet) or any other medication maintenance documentation.
- **Opportunity for Exploitation** – Upon request, owners/operators were not consistently able to provide investigators with any accounting documentation, including an account of all monies received and disbursed on behalf of a particular

client, written fee agreements, proof that the facility was not mixing its funds with client funds, and proof of annual reporting. This violates *Rules of Department of Mental Health and Developmental Disabilities Office of Licensure Chapters 0940-5-6-.03, 0940-05-6-.05, 0940-5-19-.04.*

- **Poor Physical Conditions** – Investigators observed bags of personal belongings blocking doorways, poorly lit homes, foul odors permeating the house, and stairways with poor safety measures. Such conditions violate *Rules of Department of Mental Health and Developmental Disabilities Office of Licensure Chapter 0940-5-5-.02.*

SELF-ADVOCACY

- **Lack of Services** – Upon request, owners/operators were not consistently able to provide investigators with any documentation stating that the facility was assisting residents to obtain professional services, navigate the system, and ensure residents attended appointments. This violates *Rules of Department of Mental Health and Developmental Disabilities Office of Licensure Chapter 0940-5-19-.03.*
- **Lack of Client Education** – Upon request, owners/operators were not consistently able to provide investigators with any documentation to prove that residents had been provided information about their individual rights and the facility’s grievance procedures. This violates *Rules of Department of Mental Health and Developmental Disabilities Office of Licensure Chapters 0940-5-6-.02, 0940-5-6-.06, 0940-05-19-.05.*

From the issues DLAC investigators identified, it is clear that some of Tennessee’s most vulnerable citizens are at risk of harm including abuse, neglect, and financial exploitation. While disturbing, many of the previously stated concerns have practical solutions which require immediate action at a variety of levels. Tennessee’s Department of Mental Health must enforce its authority to ensure the welfare of persons with mental illness who live in board and care homes.

TROUBLE WITH PRESCRIPTIONS

RESIDENTS IN SOME FACILITIES ARE RESPONSIBLE FOR OBTAINING AND FILLING THEIR OWN PRESCRIPTIONS, AS WELL AS MAINTAINING AND ADMINISTERING THEIR OWN MEDICATIONS, REGARDLESS OF THEIR INDIVIDUAL LEVEL OF CAPABILITY.



TAKING ACTION

ISSUE

Lack of sufficient oversight by the Tennessee Department of Mental Health (TDMH) with regard to board and care homes serving persons with mental illness.

SOLUTION

Increased oversight of board and care homes by TDMH.

ACTIONS

- TDMH will review this report to gain additional knowledge about existing conditions within board and care homes serving persons with mental illness and will utilize this knowledge as a basis to examine, improve, and implement TDMH policies and procedures.
- TDMH licensure will play a more active role to ensure continual compliance with rules in board and care homes, i.e. increase frequency of inspections including multiple and random unannounced inspections throughout the year.

ISSUE

Lack of accountability within board and care homes serving persons with mental illness creates an environment that is detrimental to residents.

SOLUTION

Increased accountability by the board and care home owners/operators.

ACTIONS

- TDMH will ensure facilities' owners/operators are educated about their responsibilities under TDMH's rules.
- TDMH will examine the use of provisional licenses for facilities out of compliance including providing increased training as a precursor to upgrading to a full license.
- TDMH will create and establish an operator driven peer support network. Such a network will increase capacity throughout this system by highlighting and building on the strengths of those board and care homes which demonstrate best practices in service provision.

ISSUE

Given the magnitude of the mental health problem in Tennessee, a high level of involvement is necessary from persons with mental illness, community agencies, mental health centers, private interest groups, families and other natural supporters of persons with mental illness in order to ensure quality board and care home services. DLAC's research indicates decidedly fewer supports and services are available for persons with mental illness than are available for persons with intellectual disabilities.

SOLUTION

Increase commitment of all stakeholders to expand the number of available supports and services for persons with mental illness.

ACTIONS

- TDMH will educate stakeholders regarding TDMH's rules governing board and care homes, expectations, and responsibilities.
- TDMH will educate stakeholders on the process for reporting compliance issues to TDMH.
- DLAC and its community partners will educate stakeholders about the current status of board and care homes including their roles, responsibilities, and issues identified.
- DLAC and its community partners will educate stakeholders about residents' rights.
- DLAC and its community partners will educate stakeholders regarding improved outcomes for persons with mental illness receiving adequate natural and professional supports.

ISSUE

Board and care homes serving persons with mental illness have failed to provide information and to educate residents about their rights and responsibilities. Therefore, residents have been unable to self-advocate for services and conditions that at least meet TDMH's prescribed minimum program requirements.

SOLUTION

Provide information, education, and assistance to build the skills and personal capacity needed by residents to self-advocate for services and living arrangements.

ACTIONS

- Board and care home owners/operators will educate residents about the facility's responsibilities.
 - Board and care home owners/operators will educate residents about their rights and responsibilities.
 - Board and care home owners/operators will educate residents about grievance procedures at the facility level.
 - Board and care home owners/operators will educate residents about filing complaints with TDMH.
 - Board and care home owners/operators will educate residents about how to report suspected abuse/neglect/exploitation.
 - Board and care home owners/operators will educate residents about how to access available community resources.
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DLAC WILL CONTINUE TO REGULARLY MONITOR BOARD AND CARE HOMES AND EXPECTS TO FIND THAT TDMH HAS REMEDIATED THE PROBLEMS IDENTIFIED IN THIS REPORT. ONCE RECOMMENDED CHANGES TAKE PLACE, TENNESSEE'S SUPPORTIVE LIVING FACILITIES WILL BE BETTER POSITIONED TO PROVIDE THE CARE AND SUPPORT NECESSARY FOR RESIDENTS WITH DISABILITIES, INCLUDING MENTAL ILLNESS. THROUGH IMPROVED STATE OVERSIGHT AND THE PARTICIPATION OF RESIDENTS AND COMMUNITY STAKEHOLDERS, TENNESSEE CAN ULTIMATELY FULFILL THE GOAL THAT SUPPORTIVE LIVING FACILITIES OFFER QUALITY BOARD AND CARE FOR ALL.

SIMPLIFIED SUMMARY

Disability Law & Advocacy Center of Tennessee (DLAC) wrote this document. DLAC is a protection and advocacy system. DLAC protects the legal rights of people with disabilities. DLAC investigates abuse and neglect.

Most people with disabilities live in the community. Most do not need help. Some people with disabilities need help to live in the community. Some live in special housing. That housing is called supportive living. That housing is also called board and care homes. Here we will call that housing board and care homes.

Some people with mental illness live in board and care homes. Some people with intellectual disabilities live in board and care homes. The Tennessee Department of Mental Health (TDMH) licenses those board and care homes.

DLAC monitored 60 board and care homes. That was in the year 2010. DLAC found problems in the homes. Most of the problems were in homes for people with mental illness.

There are rules for board and care homes. Many homes for people with mental illness did not follow the rules. This placed people with mental illness in poor living conditions. This also placed people with mental illness at risk for abuse and neglect.

DLAC wants TDMH to make board and care homes follow the rules. DLAC wants TDMH to make all board and care homes follow the same rules. DLAC thinks that will make the homes better for people with mental illness.

RESUMEN EJECUTIVO

El Centro de Ley de Incapacidad y Apoyo de Tennessee (DLAC) es el sistema de protección y abogacía designado para el estado de Tennessee. DLAC fue asignada por el gobierno federal para proteger y defender los derechos de las personas con discapacidades. En acuerdo con su autoridad, DLAC investiga las denuncias de abuso y negligencia y monitorea las instituciones para garantizar la protección del daño, el abandono y la explotación financiera, y también garantizar una calidad alta de servicios disponibles para las personas con discapacidades.

En actualidad, las instalaciones de apoyo para las personas con enfermedades mentales y personas con discapacidades intelectuales son licenciados por el Departamento de Salud Mental de Tennessee (TDMH). Instalaciones de apoyo de vida son conocidas como casas de apoyo de vida, hogares colectivos, casas de huéspedes, o hogares de alojamiento y asistencia en sus comunidades respectivas en Tennessee. Por todo este informe, instalaciones autorizadas de apoyo de vida son mencionadas por el nombre más comúnmente usado “hogares de alojamiento y asistencia.”

Este documento expone la información recopilada por los investigadores de DLAC durante varias visitas a 60 hogares de alojamiento y asistencia en Tennessee durante el año 2010. Treinta (30) de los hogares sirven a personas con discapacidad intelectual; 30 sirven a personas con enfermedad mental. DLAC documentó una diferencia notable entre los hogares autorizados para las personas con discapacidad intelectual y los para las personas con enfermedad mental.

Para reconciliar esta contradicción, DLAC desafía TDMH para duplicar los estándares de licenciatura y revisión de los hogares para los residentes con discapacidad intelectual y aplicar esos mismos estándares a los hogares para los residentes con enfermedad mental. Personas con discapacidad intelectual y personas con una severa enfermedad mental persistente son particularmente vulnerables a daño. Por lo tanto es recomendable tener reglas similares para todos los hogares licenciados por el estado. DLAC tiene confianza que la implementación de estas recomendaciones proveerá las condiciones necesarias para ayudar a las personas con enfermedades mentales vivir en entornos seguros y ser más autónomos en sus arreglos de vida.



DISABILITY LAW & ADVOCACY CENTER
of Tennessee

The mission of DLAC is to advocate for the rights of Tennesseans with disabilities to ensure they have an equal opportunity to be productive and respected members of our society.

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