Salmon

Disability Rights Nebraska

Since 1978, Disability Rights Nebraska, an independent, private, nonprofit agency has served as Nebraska's Protection and Advocacy (P&A) system to protect the rights and interests of persons with disabilities.[1]

Disability Rights Nebraska engages in monitoring of institutional facilities; investigates allegations of abuse and neglect; pursues administrative, legal, and other appropriate remedies; and provides information, referral, rights/advocacy, and training.

Assisted Living Facilities for People with Mental Illness Across Nebraska

As part of its monitoring activities, Disability Rights Nebraska has become intimately familiar with numerous privately-owned assisted-living facilities and mental health centers across the state where residents' primary disability is severe and persistent mental illness. These facilities are often hidden from the public in rural communities across Nebraska or in larger cities, with the public unaware of the conditions that persist for the residents who are forced from one location to the next. Prescott Place and Bel-Air are two local facilities that we monitor, but are far from the only ones. Individuals with mental illness also reside in assisted living facilities in places like Palmer and Inavale; Grand Island and North Platte; Gothenburg and Omaha. And the list goes on. These facilities are all over our state and what ties them together is not the services they provide; rather, it is the deplorable conditions, the neglect and abuse that takes place, and congregation and isolation the likes of which most of us cannot imagine. As one former resident of Hotel Pawnee Assisted Living Facility said, "I felt like a rat trapped in a cage. It's degrading to your spirit to live there."

Residents at these places often spend upward of $1200 per month in order to live in a room with two to three other people that smells of urine and feces. Privacy in these rooms is nonexistent, and daily activities include a regiment of scheduled smoking and watching TV. The services paid for by residents, and provided by the assisted-living facility, often include nothing more than the bed-bug infested bed they sleep on and provision of substandard food. Payment for these "services" is made through public benefits each

[1] 42 U.S.C. § 15001 *et seq*. (DD Act)

individual receives from the Social Security Administration through SSI or SSDI. If an individual's Social Security Benefits are too low to pay $1200 per month, the State of Nebraska pays the balance through State supplementation, administered through the Department of Health and Human Services. People at the Lincoln Regional Center are not treated this poorly.

The Department of Health and Human Services Division of Public Health, where the Regulation and Licensure Unit is housed, is charged with responding to and investigating allegations of assisted-living facility licensure violations. The employees of the Division tasked with surveying the conditions generally do a very good job in performing the surveys and drafting reports that respond to the allegations. For example, a survey of Hotel Pawnee, a now nonexistent assisted-living facility in North Platte, NE, showed thirty-six serious licensing violations through a survey conducted in May of 2012. Unfortunately, the Licensure Unit failed to respond to these substantiated violations for over one year. The violations in this instance included, among numerous others, failure to maintain proper air temperature. At different points, neither the air conditioning nor heater worked at Hotel Pawnee. For residents taking psychotropic medications, this could have been life-threatening. And yet, the Unit did nothing, except assess a $25 per day fine on Hotel Pawnee for failing to keep in-door temperatures below 85 degrees Fahrenheit. Over the course of several years, Hotel Pawnee was cited for dozens upon dozens of licensing violations that threatened the lives of its residents. Despite the urgency of these violations, the Licensure Unit did nothing meaningful to remedy the problems. In the end, the only reason Hotel Pawnee closed was because it could no longer pay its bills.[2]

Unfortunately, the conditions at Hotel Pawnee are the norm throughout the State and can be seen at numerous other assisted-living facilities, and documented through the Licensure Unit's investigations. These conditions are not the exception; they are the norm. The Licensure Unit's lackluster response to any violations is also, unfortunately, the norm.

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[2] *See DHHS report: Hotel Pawnee in violation of state regulations,* NPTelegraph.com, available at http://www.nptelegraph.com/breaking_news/dhhs-report-hotel-pawnee-in-violation-of-state-regulations/article_6614c2d8-d1ee-11e1-9727-0019bb2963f4.html) (last visited October 5, 2015); *This could be the end for the Hotel Pawnee.*, NPTelegrapoh.com, available at http://www.nptelegraph.com/news/this-could-be-the-end-for-the-hotel-pawnee/article_2eb5cee2-dd77-11e1-b724-0019bb2963f4.html (last visited October 5, 2015); *see also Pawnee's doors stay open*, NPTelegrapoh.com, available at http://www.nptelegraph.com/news/pawnee-s-doors-stay-open/article_14697035-1260-5ddd-97b7-ebe3492a397e.html (last visited October 5, 2015).

If the population that lived at these assisted-living facilities consisted of anyone other than people with severe and persistent mental illness, they would simply leave because they could get the services they need elsewhere. But, because Nebraska has repeatedly failed to provide the necessary services and supports, people with severe and persistent mental illness have nowhere else to go. They are forced to live in institutions covered in filth. LB 1083 is largely responsible for these unintended consequences.

LB1083's Broken Promise

The Behavioral Health Reform Act, LB 1083, was passed by the Nebraska Legislature in 2004.[3] It sought to address an overreliance on the state's institutional regional centers, and move toward community- based services. LB 1083 promised to deinstitutionalize Nebraska's behavioral health system and move people out of the regional centers and "into the community." Indeed, the Behavioral Health Oversight Commission (BHOC) noted in its 2008 report that,

> Consistent with advances in research and treatment, evolving best practices, the legal and civil rights of those with mental illness or other disability as established in the U.S. Supreme Court *Olmstead* decision, and the advocacy of consumers, families, and professionals alike, LB 1083 envisioned and mandated the provision of services closer to home, family, and support services and in the least restrictive setting.[4]

Under LB 1083, the Division of Behavioral Health and the six Behavioral Health Regions are mandated by statute to implement comprehensive state-wide planning.[5] The Division has failed to do so, and the Regions have been left without direction from the Division. A majority of residents do not know about the regions or the services they offer. Many report having no case manager they can call and have no idea how to regain independence. The numerous failures of the Division of Behavioral Health to implement any comprehensive state-wide planning has resulted in the assisted-living facilities we know today, and a citizenry who are denied participation as full citizens.

Despite LB 1083's promise to deinstitutionalize, one institution has been replaced with another, individuals do not receive the treatment they need, and the cycle of hospitalization and discharge continues.

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[3] Neb. Rev. State. §§ 71-801-71-831 (2004) (amended 2012).
[4] JIM JENSEN BEHAVIORAL HEALTH OVERSIGHT COMMISSION OF THE LEGISLATURE FINAL REPORT, at 1 (2008), *available at* http://www.thekimfoundation.org/html/pdf/BHOC%20Final%20Report%207-1-08.pdf (last visited May 10, 2013).
[5] Neb. Rev. Stat § 71-806(2).

Mental Health Services and Supports Must be Administered in the Most Integrated Setting

Title II of the Americans with Disabilities Act (ADA) makes it illegal for public entities, namely state and local governments to deny qualified individuals with disabilities the benefits of their programs, services or activities. [6] The regulations which implement Title II mandates state governments to administer services "in the most integrated settings appropriate to the needs of qualified individuals with disabilities.[7] This is often referred to as the ADA "integration mandate." The ADA's integration mandate is implicated where a public entity administers its programs in a manner that results in unjustified segregation of persons with disabilities. More specifically, a public entity may violate the ADA's integration mandate when it: (1) directly or indirectly operates facilities and or/programs that segregate individuals with disabilities; (2) finances the segregation of individuals with disabilities in private facilities; and/or (3) through its planning, service system design, funding choices, or service implementation practices, promotes or relies upon the segregation of individuals with disabilities in private facilities or programs.[8]

The U.S. Department of Justice has been involved in numerous *Olmstead* enforcement actions involving private facilities. For example, after a lengthy investigation of North Carolina's mental health service system, the Department issued a findings letter in July of 2011 concluding that the State is violating *Olmstead* by administering its system in a manner that unnecessarily segregates persons with mental illness in large, privately-owned adult care homes. The Department entered into a settlement agreement with North Carolina on August 23, 2012. In addition to other provisions, the Agreement expands access to community-based supported housing – integrated housing that promotes inclusion and independence and enables individuals with mental illness to participate fully in community life.[9]

Nebraska's failures to provide mental health services in the most integrated setting are a violation of the ADA and *Olmstead*.

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[6] 42 U.S.C. §§ 12131-34 (1990).
[7] DOJ Nondiscrimination on the Basis of Disability in State and Local Government Services, 28 C.F.R. § 35.130(d) (2010).
[8] *See* 28 C.F.R. § 35.130(b)(1) (prohibiting a public entity from discriminating "directly or through contractual, licensing or other arrangements, on the basis of disability"); U28 C.F.R. §35.130(b)(3) (prohibiting a public entity from "directly, or through contractual or other arrangements, utilizing criteria or methods of administration" that have the effect of discriminating on the basis of disability").
[9] Settlement Agreement, *U.S. v. North Carolina*, No. 5:12-cv-557 (E.D.N.C. filed August 23, 2012), *available at* http://www.ada.gov/olmstead/documents/nc-settlement-olmstead.pdf (last visited May 7, 2013).

A Call to Action

Disability Rights Nebraska is prepared to address the problem through a variety of strategies including legislative action, coalition building and systemic litigation. We believe this is an opportunity for the new administration to take action and work with stakeholders, community organizations and the public to address this tragedy. We believe this is not only an opportunity for this administration, but we believe this administration is one that can solve these problems and collaborate with stakeholders.

In the short term, Disability Rights Nebraska urges lawmakers to introduce a legislative interim study resolution to investigate the issues surrounding conditions in assisted-living facilities and the provision of mental health services for residents in these assisted-living facilities. We call on all stakeholders to create a coalition to address these issues.

Possible solutions to the problems at hand must first, and foremost, be one that comes into compliance with the ADA and *Olmstead*. People must truly be served in the community and in the most integrated setting possible. Disability Rights Nebraska is prepared to do what is necessary and welcomes the opportunity to work with the legislature, the administration, and stakeholders to ensure that the oft forgotten are finally afforded the opportunity to live a full and meaningful life.