



## **RIGHTS AND GRIEVANCE PROCESSES FOR CONSUMERS OF BEHAVIORAL HEALTH**

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## **Project Introduction**

This report is provided pursuant to an agreement between the Board of Regents of the University of Nebraska on behalf of the University of Nebraska-Lincoln, and Region 5 Systems on behalf of the Consumer Family Coalition.

## **Statement of the Problem**

In recent years, both the federal and state governments have addressed human rights of persons with mental illness (“consumers”). Currently, a patchwork approach has evolved to protect the rights of consumers in society. There is no single cohesive process to safeguard rights of consumers, or for consumers to report grievances. Rather, the process is highly dependent on the factual situation, the individual federal or state laws and jurisdiction involved, the status or location of the consumer in the behavioral health system, the financing and licensing of service providers, and other issues.

Additionally, the securing of rights through effective grievance processes is affected by more than just legal structures. Consumers are particularly vulnerable because they may lack the functioning to navigate a complicated system and utilize grievance processes, or even exercise or be aware of their rights. Consumers are often dependent on some degree to providers – sometimes for the most basic necessities - and there is an essential power imbalance in the relationship between consumers and providers. Consumers may also be socially isolated and lack support from family and friends for help. Thus, geography, poverty, and overall environment are all factors impacting consumers’ ability to exercise grievance processes. There is a similar lack of professional assistance resources. Federal and state regulatory agencies, and disability rights or consumer advocacy organizations are spread thin and underfunded or understaffed. Obtaining private legal assistance is an option many consumers may not be able to afford.

For these reasons, consumers' inability to effectively secure rights or exercise grievances contributes to social marginalization and further vulnerability. A major gap in this area is the lack of empirical data to determine the extent of the problem, causes, and potential solutions. This lack of research is likely due to a combination of the sensitivity of the issue, lack of cohesive reporting systems, and inaccessibility to consumer populations. Although a small body of research has developed in related areas, there appears to be no well-established and comprehensive research approach specific to this area of consumer rights and grievance processes. However, anecdotal information reported in the media, and associated research (e.g. elder abuse statistics), indicate that the problems facing consumers are likely very widespread.

## **Literature Review: Consumer Rights and Grievance Processes**

There are a number of studies suggesting that violations of consumer rights in the behavioral health system are widespread. For example, it is believed that abuse of residents in long-term care facilities occurs on a regular basis, though estimates of scope vary widely (Bond & Butler, 2013; Dong, Chen, Chang, & Simon, 2012; Lachs & Pillemer, 1995; McDonald et al., 2012). Schiamberg found that 24% of randomly selected adults with relatives in nursing homes reported being abused by staff (2012). Pillemer and Moore's survey of intermediate care and nursing home professionals in New Hampshire found that 10% of staff admitted to committing physical abuse, and 40% admitted to committing psychological abuse. Over 80% of the surveyed staff admitted to witnessing psychological abuse of residents/patients (1989). Boyles' study of nursing homes in the Atlanta area found that 44% of residents reported having been abused, 38% had witnessed abuse, and 95% experienced or witnessed neglect (2000). Castle's study of nurse aides in Pennsylvania found that 28% reported witnessing intimidation of nursing home residents by staff (2010). Cooper and colleagues' meta-analysis of studies

on elder abuse estimated that approximately 1 in 6 professional care staff commit psychological abuse of residents (2008).

Despite these select studies, reporting or admission of abuse of residents in facilities is believed to be low for a number of reasons, including fear of retaliation (Allen, Kellett & Gruman, 2004; Pillemer & Bachman-Prehn, 1991), incapacity or inability to report by residents (Gorbien & Eisenstein, 2005; Harris & Benson, 2000), or unwillingness to report or admit to abuse or neglect by professional caregiving staff or management (Bergeron & Gray, 2003; Meddaugh, 1993). Additionally, there are few standardized definitions of what actually constitutes abuse or neglect, use of measures validated for reliability, or scientifically-sound sampling studies to gauge the prevalence of abuse or neglect in long-term care facilities (Cooper, Selwood & Livingston, 2008; Fulmer, Guadagno & Connolly, 2004). In community care contexts, even less is known because of the absence of consistent formal reporting mechanisms, and likelihood that caretakers are family members (Fitzpatrick & Hamill, 2010; Schiamberg & Gans, 2000). Similarly, there is a dearth in research about rights violations among day service providers generally, halfway homes, or other environments specifically serving behavioral health consumers in the community.

Studies that do exist suggest that individuals with higher prevalence of cognitive impairments or behavioral problems may be particularly at risk of abuse by caregivers (Arling & Williams, 2003; Connor et al., 2011). The most vulnerable - those who need assistance with daily living activities, physical functioning, and serious behavioral conditions - may be at risk for multiple forms of abuse (Post et al., 2010). It is hypothesized that those most in need of care may be at such risk due to the fact or perception that there will be no retribution due to their social isolation or cognitive abilities (Pillemer & Bachman-Prehn, 1991; Pillemer & Finkelhor, 1989), and the high levels of emotional stress or strain experienced by caregiving staff (Pillemer & Moore, 1989; Jogerst, Daly, Dawson, Peek-Asa & Schmuck, 2006). Wider contextual issues may also be a factor in abusive environments, such as lack of training or

oversight (Braun, Suzuki, Cusick, & Howard-Carhart, 1997; Hudson, 1993), presence or absence of social support for residents/consumers (Dong & Simon, 2008; Godkin, Wolf & Pillemer, 1989), and institutional size and staffing characteristics (Kayser-Jones et al., 2003; Phillips & Guo, 2011). The end result is that those most vulnerable to abuse or neglect may be the most voiceless. Residents of institutional care settings are likely to be of old age, physically frail or vulnerable, and have a variety of cognitive, behavioral, or psychological conditions or impairments (Bragg, 1997; Brown, Lapane & Luisi, 2002, Jones, 2002). Residents may have few family caregivers or visitors to provide social support (Fessman & Lester, 2000; Hicks, 2000; Poulshock & Deimling, 1984), and little financial resources other than Medicaid or other entitlement benefits (Ness, Ahmed & Aronow, 2004). The ability to hire an attorney, for example, may be financially unviable for many consumers. Many may not have the ability to simply navigate the complicated system of rights or complaint processes that do exist.

It should be noted that direct physical or psychological abuse of an individual is only one type of violation of an individual's rights, safety, well-being, or dignity, which could occur in the behavioral health care context. A violation, as defined in Black's Law Dictionary, is an "injury; infringement; breach of right, duty or law" (1991). Merriam-Webster defines a violation as "the act of doing something that is not allowed by a law or rule....the act of ignoring or interfering with a person's rights" (1993). State laws pertinent to the prohibition of abuse of vulnerable persons in a caregiving context define violations or abuse in similar fashions. For example, Nebraska defines abuse as "[a]ny knowing, intentional, or negligent act or omission on the part of the caregiver...or any other person which results in physical injury, unreasonable confinement, cruel punishment, sexual abuse, exploitation, or denial of essential services to a vulnerable adult" (Ne. Rev. Stat. § 28-351). The state of Florida defines abuse as "any willful or threatened act...likely to cause significant impairment to a vulnerable adult's physical, mental, or emotional health" and "neglect" as a "failure or omission on the part of the caregiver or vulnerable adult to provide the care, supervision, and services necessary to maintain the physical and mental health of

the vulnerable adult, including but not limited to, food, clothing, medicine, shelter, supervision, and medical services, that a prudent person would consider essential for the well-being of a vulnerable adult” (Fla. Stat. Ann. § 415.102). New York state has defined both “active neglect” and “passive neglect”, respectively, as “willful” or “non-willful” failures of a caregiver to fulfill caregiver functions, as well as specific definitions for “emotional abuse” (threat, humiliation, intimidation, to frighten or isolate) and “financial exploitation” (improper use of funds, property or resources) (N.Y. Soc. Serv. Law § 473). The state of Utah has specific definitions for “intimidation” (“communication through verbal or nonverbal conduct which threatens deprivation of money, food, clothing, medicine, shelter, social interaction, supervision, health care, or companionship”) as well as for “isolation” (preventing a vulnerable adult from having contact or communication with another person) (Utah Code Ann. § 62A-3-301).

Data from the National Ombudsman Reporting System (NORS) provides an overview of the breadth and depth of violations of resident rights that occur within the nation’s long term care facilities. The NORS was developed by the Administration on Aging within the U.S. Department of Health and Human Services in 1995 (DHHS, 2003). NORS aggregates reporting data from the nation-wide State Long Term Care Ombudsman Program, created by Congress through the Older Americans Act Amendments of 1978 to facilitate resolution of complaints by nursing home residents. There are ombudsman programs participating in this system in every state, operating in a network of regional or local programs (Estes, Zulman, Goldberg & Ogawa, 2004; Hollister & Estes, 2013). NORS data from 2010 show that a total of 157,962 complaints were made nation-wide. Complaint categories included those pertaining to resident rights (34%), resident care (31%), quality of life (21%), administration (5%), and other complaints not directed at a particular facility (8%). Of the three largest categories of complaints for 2010, they could be further categorized into the following sub-groups: For resident rights, there were complaints related to abuse/neglect/exploitation (21%), access to information (9%), admission/transfer/discharge (22%), and

autonomy/preferences/privacy (35%). Resident care complaints were sub-categorized into care (85%), rehabilitation (13%), and restraints (2%). Quality of life complaints were sub-categorized into activities/social services (26%), dietary (31%), and environmental (43%) (NORS, 2010).

Thus, a remarkably high number of complaints made under NORS are not for instances of alleged abuse or neglect, but for other reasons ranging from diet to administrative issues. Table 1 shows national and Nebraska NORS 2010 complaint data. It should be noted that there are limitations to the NORS data. For example, it has been recognized that reporting approaches used by individual state or local ombudsman programs are not consistent (DHHS, 2003). Additionally, NORS is directed generally at complaints raised by nursing home residents or people acting on their behalf. The federal Protection and Advocacy (P&A) system, a broad network based on federal law and requirements (Gross, 1998), does also maintain monitoring, investigating, and reporting mechanisms for persons with disabilities, but there is no uniform nationwide reporting system as comprehensive as that as NORS. Most importantly, although it can be generally assumed that a significant amount of nursing home residents covered under the long term care ombudsman program are also consumers of behavioral health services, the populations are not the same, and the NORS may not account for the particular needs or dynamics facing behavioral health consumer populations. Often times, state agencies that finance behavioral health services – i.e. a state department of behavioral health or mental health – is not the same agency or division with jurisdiction over nursing homes. The NORS data may serve as a rough guide to the experiences of behavioral health consumers, but is clearly not an exact fit.

**Table 1. National Ombudsman Reporting System Data 2010, Nationwide and Nebraska**

	<b>NATIONAL</b>	<b>NEBRASKA</b>
<b>RESIDENT RIGHTS</b>	<b>53,621</b>	<b>1,025</b>
Abuse, gross neglect, exploitation	11,284 (21%)	22 (5.5%)
Access to information by resident or resident's representative	4,669 (8.7%)	35 (8.7%)
Admission, transfer, discharge, eviction	11,540 (21.5%)	92 (22.8%)
Autonomy, choice, preference, exercise of rights, privacy	18,579 (34.6%)	190 (47.2%)
Financial, property	7,549 (14%)	64 (15.9%)
<b>RESIDENT CARE</b>	<b>49,150</b>	<b>229</b>
Care	41,777 (85%)	171 (74.7%)
Rehabilitation of maintenance of function	6,620 (13.5%)	55 (24%)
Restraints – Chemical and physical	753 (1.5%)	3 (1.3%)
<b>QUALITY OF LIFE</b>	<b>33,946</b>	<b>172</b>
Activities and social services	8,991 (26.5%)	45 (26.2%)
Dietary	10,395 (30.6%)	66 (38.4%)
Environment	14,560 (42.9%)	61 (35.5%)
<b>ADMINISTRATION</b>	<b>8,747</b>	<b>41</b>
Policies, procedures, attitudes, resources	2,078 (23.8%)	12 (29.3%)
Staffing	6,669 (76%)	29 (70.7%)
<b>NOT AGAINST FACILITY</b>	<b>12,498</b>	<b>180</b>
Certification/licensing agency	236 (1.9%)	2 (1.1%)
State Medicaid agency	1,345 (10.8%)	24 (13.3%)
System/others	10,917 (87.4%)	154 (85.6%)

Source: [http://www.aoa.gov/aoa\\_programs/elder\\_rights/Ombudsman/National\\_State\\_Data/2010/Index.aspx](http://www.aoa.gov/aoa_programs/elder_rights/Ombudsman/National_State_Data/2010/Index.aspx)

What exactly are the rights of individuals in the behavioral health system? From a normative and conceptual perspective, a “right” as defined in Black’s Law Dictionary is “a power, privilege, faculty, or demand, inherent in one person and incident upon another” (1991). Traditionally, “rights” may be framed as deriving their value as rights through a foundation in origin. For example, the French Declaration of the Rights of Man and the Citizen, declares rights as those which are “natural, inalienable, and sacred” (1789). Similarly, the American Declaration of Independence frames rights as those that are “truths to be self-evident...endowed by their Creator” (1776). As inherent and inalienable rights – regardless of their origin – they derive their modern power vis-à-vis force of law recognized by a formal community. The rights enumerated in the Constitution of the United States, for example, are those that

are recognized by “We the People” in order to “establish Justice...promote the general Welfare, and secure the Blessings of Liberty” (1787), and have become the basis for American law. Likewise, the enumerated rights under the United Nations’ Universal Declaration of Human Rights are those recognized by the member-states in “recognition of the inherent dignity and of the equal and inalienable rights of all members of the human family” (1948). Through the recognition of rights, community members are thus bound to respect and protect those rights through affirmative acts or omissions (Beitz, 2003; Koh, 1998). Within the international framework of rights, theoretically all people enjoy those rights that have been acquired vis-à-vis positive obligations through international law. Because of the de facto system of national sovereignty, ones’ actual rights are those recognized within the applicable national legal system. In the United States, a person’s rights are derived from a patchwork of federal, state, and local legal systems.

A variety of federal laws provide directly applicable protections to behavioral health consumers. The overall scope, and regulatory or enforcement approach of the federal laws differ by individual statute, and taken together, amount to a patchwork approach. Early recognition of rights at the federal level included those focusing on the institutionalized developmentally disabled. The Developmentally Disabled Assistance and Bill of Rights Act of 1975 recognized that “[p]ersons with developmental disabilities have a right to appropriate treatment, services, and habilitation for such disabilities” (1975). Congress followed this with the Developmental Disabilities Assistance and Bill of Rights Act of 1984, which was passed to “establish and operate a system which coordinates, monitors, plans, and evaluates services which ensures the protection of the legal and human rights of persons with developmental disabilities” (1984). This series of acts was later updated in the Developmental Disabilities Assistance and Bill of Rights Act of 2000, which expanded its scope to cover those with developmental disabilities living in community settings (2000). Section 109 of the 2000 act recognizes rights of individuals with developmental disabilities, such as the right to care free of abuse, neglect, and exploitation, prohibits

certain acts such as excessive restraints, and enumerates certain programmatic standards. The act generally serves to provide financial support to state councils on developmental disabilities (§121 et seq.), as well as state protection and advocacy systems (§141 et seq.). A landmark statute was the 1980 Mental Health Systems Act, which was the first piece of federal legislation that contained a comprehensive bill of rights for consumers of mental health services (1980). The bill of rights included the rights to appropriate treatment (§ 501 (1)(A)), ongoing involvement in treatment planning (§ 501 (1)(C)), a humane treatment environment (§ 501 (1)(G)), and right to a fair, timely, and impartial grievance process (§ 501 (1)(L)). Much of the legislation however was later defunded or amended as part of a new budget act (Perlin, 1986).

As noted previously, the national framework for Long-term Care Ombudsman Program was created in 1978 as an amendment to the Older Americans Act (1965). Every state and territory has a long-term care ombudsman program to facilitate resolution of complaints that residents of nursing and assisted living homes may have, usually established through a state or local agency on aging or health department (Adcock, 2013). The ombudsmen are trained professionals or volunteers who serve to advocate for residents, provide information, and facilitate problem-solving related to complaints (NORC, n.d.). However, the enabling or associated legislation does not itself directly enumerate a bill of rights for residents. The primary source for federally-recognized rights lies within funding legislation for participating facilities. Under Medicaid, the federal government mandates requirements for participating states. Nursing facilities (42 USC 1396r, §1919 et seq.), for example, are required to protect and promote free choice; freedom from restraints, physical and mental abuse, and involuntary seclusion; participation in resident and family groups; and privacy and confidentiality (§1919 (c)(1)(A), as well as transfer and discharge rights (§1919 (c)(2)), access and visitation rights ((§1919 (c)(3)), and equal access to care (§1919 (c)(4)), among other requirements.

Individual states will also have accompanying rights for residents and consumers enumerated in their facility or service licensing laws. These laws generally attempt to define minimum standard requirements, promote rights and protections, and establish a framework for complaints or grievances above those that exist federally. The state of Florida is considered to have a robust statutory approach to resident and consumer rights in assisted living facilities and similar areas. Florida requires nursing home licensees to provide residents with rights to civil and religious liberties, private communication, freedom from abuse and unnecessary restraint, right to be treated fairly and with dignity, right to refuse treatment, and numerous other protections (Fl. St. § 400.022, 2013). The Nebraska Health Care Facility Licensure Act (Ne. Rev. Stat. § 71-401) has similar requirements. It enumerates resident/patient rights that must be protected as a condition of licensure for assisted living facilities, adult day service, children's day service, health clinics, hospitals, skilled nursing facilities, and home health care. Licensed assisted living facilities in Nebraska, must therefore protect a resident's right to be treated with dignity and provided care by competent staff, participate in care and treatment decisions, receive visitors, be free of abuse and neglect, participate in resident groups, and other rights (175 NAC 4-006.04).

In both federal and state law, enforcement of consumer rights may take place in at least three general ways. The predominant approach taken is that service providers or facilities are expected to enforce patient rights on their own. Both federal and state law attempts to accomplish this outcome by establishing a legal framework for facilities and service providers to implement and administer a rights, grievance, and redress policy. The second approach is for outside enforcement investigators from regulatory agencies to conduct periodic reviews of facilities or services, whether on the basis of a systematic enforcement plan, contractual or licensing basis, complaints from individuals, or other regimens. Thirdly, individual consumers may initiate private lawsuits on their own (Harrington, Mullan & Carrillo, 2004; Walshe & Harrington, 2002; Wilson, 1978).

The limitations of the second and third approaches should first be acknowledged. In regards to agency investigations, it should be noted that there are a variety of structural issues that may impede proper regulation of facilities (Harrington & Carrillo, 1999). A major issue is the lack of funding to support adequate surveying and monitoring operations of facilities (Kelly, Liebig & Edwards, 2008; Walshe & Harrington, 2002). There may be fragmented or duplicative regulatory operations that are not coordinated well, and result in confusion or gaps (Angelelli, Mor, Intrator, Feng, & Zinn, 2003; Miller & Mor, 2008; Walshe, 2001). Private causes of action against long-term care facilities or other residential services are becoming more commonplace, and some have had considerable impact (Johnson, Dobalian, Burkhard, Hedgecock & Harman, 2004; Stevenson & Studdert, 2003). However, law suits are typically only pursued against facilities when they involve deaths, serious injuries, or forced transfers, and thus may either not be suitable or not be viable options for many consumers or residents of facilities (Bragg, 1997; Phan, 2002). Legal aid, advocacy and consumer protection groups do exist to help consumers on pro bono or low cost bases, but are often stretched thin and may not be able to help all those in need.

For these reasons, in both the state and federal law frameworks, consumer or resident rights are primarily self-enforced. Legal requirements for facilities or service providers to notify consumers of their rights and grievance processes are intended to facilitate self-enforcement. This approach gives facilities and service providers flexibility to both provide notice and create grievance processes, outside of generalized requirements to do so. For example, the federal requirement for notice in nursing homes under Medicaid provisions simply mandates that facilities “inform each resident, orally and in writing at the time of admission to the facility, of the resident’s legal rights during the stay” and “make available to each resident...a written statement of such rights” (42 USC 1396r, §1919 (c)(1)(B)). It also recognizes a “right to voice grievances with respect to treatment or care that is (or fails to be) furnished, without discrimination or reprisal for voicing the grievances and the right to prompt efforts by the facility to resolve grievances the resident may have” (42 USC 1396r, §1919 (c)(1)(A)(vi)). This also includes a

“posting of names, addresses, and telephone numbers of all pertinent State client advocacy groups such as the State survey and certification agency, the State licensure office, the State ombudsman program, the protection and advocacy network, and the Medicaid fraud control unit” (42 CFR 483.10).

State laws offer a similar approach, essentially mandating a notice of requirement and grievance process, but not an overly detailed description of how to operationalize those requirements. For example, for licensed nursing homes in Florida, the state requires oral and written notice of resident rights with phone numbers for watchdog and advocacy agencies, a written training plan and provision of resident rights training to staff, and requires random interviews with residents about their exercise of rights during state licensing reviews (Fl. St. § 400.022 (2)-(3), 2013). The interpretive guidelines to the statutory requirements call for inspectors to interview residents and family members to determine if residents are aware of their rights, how to file grievances, if staff assistance is provided, whether grievances are responded to and resolved, to what extent family members are aware of grievance rights, and similar items. Similarly, Nebraska requires that licensed assisted living facilities “must provide residents their rights in writing upon admission and for the duration of their stay” which includes the right to “[v]oice complaints and grievances without discrimination or reprisal and have those complaints/grievances addressed” (175 NAC 4-006.04). Each facility “must establish and implement a process for addressing all grievances received from residents” which includes “a procedure on submission of grievances available to residents,” “documentation of efforts to address grievances,” and assurance that “[t]he telephone number and address of the Department [of Health and Human Services] is readily available to residents, employees and others who wish to lodge complaints or grievances” (175 NAC 4-006.04a).

In theory, it is hoped that self-enforcement works through a combination of proper notice, staff training, the active involvement of residents, consumers, and family members, and the presence or availability of various monitoring or advocacy elements such as the state ombudsman program or

licensing investigators. In practice, this structure leaves large gaps. Consumers are essentially faced with two options if they are unsatisfied with their care or treatment experiences. They may either leave the service or facility, or they may voice complaints or grievances (Schlesinger, Mitchell, & Elbel, 2002). Generally speaking, the option to simply leave or even threaten to leave a service or facility is not realistic for many consumers if they have chronic illnesses, are physically frail or cognitively impaired, live in small communities without different care options, or otherwise lack the means to change providers. The second option consumers have is to voice their complaints or grievances. However, they may not do so for a variety of reasons. A principal barrier is the fact that consumers are dependent on care—and in many cases dependent on food, shelter, and basic requirements as well if they are living in an institutional facility. Residents of such facilities or consumers fear retaliation for complaining about staff or services (Page, Conner, Prokhorov, Fang & Post, 2009; Schlesinger, Mitchell, & Elbel, 2002; Stevenson, 2005). Consumers may be unaware of grievance processes, or the existence of services to assist them in filing grievances or voicing complaints, such as ombudsmen or advocacy agencies (Kaye & Monk, 1988). If consumers are aware of grievance processes, the details of the process and filing requirements may be too complicated or hard to understand. Researchers have found, for example, that statements of patients' rights are generally written in ways that require a higher reading level than that of the average member of the general public (Paasche-Orlow, Jacob, Hochhauser, & Parker, 2009).

There is little empirical evidence to indicate whether or not grievance or complaint processes are effectively or successfully used in this context. This may be because of the difficulty of obtaining research access to behavioral health consumer populations, the sensitivity of the issues surrounding grievances, or hesitation by providers or responsible regulatory agencies to grant access to data to researchers. There has, however, been a body of literature related to ombudsman programs in nursing and skilled-care facilities. Kaye and Monk conducted structured surveys of a convenience sample of nursing home residents and staff about the perceived effectiveness of ombudsman grievance facilitation

activities. They found that approximately one in three residents was aware of the ombudsman program, and less than 10% had ever filed a grievance. Older residents, minorities, women, and lesser educated residents were found to be significantly less likely to be aware of their rights or the ombudsman program (Kaye & Monk, 1988). A study of complaints among one state's 261 nursing homes also found that male residents were more likely to file complaints than females, suggesting that gender may play an impact in the willingness to participate in grievance processes (Allen, Nelson, Graman & Cherry, 2006). A review of complaints made to a long-term care ombudsman program in Connecticut found that complains about resident rights among sampled nursing homes were the second most common among residents, following complaints about care. However, the study researchers found that the presence of volunteer resident advocates within facilities positively correlated with the number of complaints issued. This suggests that having more trained volunteer advocates knowledgeable of rights and complaint processes within facilities increases the exercise of such rights (Allen, Klein & Gruman, 2003).

It should be noted that it is unclear exactly how knowledge of consumer rights, or factors that might facilitate the exercise of rights – such as the presence of ombudsman programs or advocacy workers – impacts actual care quality. Having a high number of complaints, for example, may be an indication that a facility has poor quality, or on the other hand it may mean that the facility or provider has a strong culture for grievance and complaint filling, or both. The presence of many complaints could thus be a good or a bad indication. Cherry found that the long term presence of ombudsman was correlated with quality of care among assisted living/intermediate care facilities, but it was not clear if the presence served to prevent quality problems from manifesting, or address quality problems after they have developed (1991). Stevenson found in an examination of complaints data from Massachusetts nursing homes that the number of complaints per facility did not correlate with institutional size, but did align with deficiencies found in state agency licensing surveys. This suggests that resident complaints – if made – are an indicator of whether residential facilities are meeting state regulations (Stevenson, 2005).

It could be that rights' advocate activities are tipping off state regulatory agencies about violations and care quality issues, but studies are not conclusive on exactly how complaint and grievance processes affect the environment and outcomes (Allen, 2006). Because of the difficulties presented with doing research in these areas, much of the knowledge in this area is based on limited case studies, convenience samples, anecdotal information or hypotheses.

However, it should be highlighted again that nursing homes and skilled care facilities differ from services or facilities that may be primarily serving behavioral health consuming populations. Although there are needs and populations that overlap, it is important to recognize that regulatory mandates and scopes may differ. Consumer rights offices of state health services, for example, may only have jurisdiction over those services that provide behavioral or substance abuse services. One of the only studies conducted on perceptions and experiences with grievance processes in a behavioral health setting was conducted by Old Dominion University in 2013. They surveyed and interviewed consumers, users of complaint processes, advocates, human rights committee members, and providers across multiple sites in Virginia. They found that about 2/3 of consumers who had used the formal complaint process felt it was easy to learn about the procedure, but about a 1/3 did not agree the process itself was easy to understand. They also found that most respondents of all categories thought that the complaint process was timely, but consumers were less likely to think so than providers. The researchers also found significant differences between how providers and consumers view complaint processes, although there was a general agreement that more training needs to be conducted in grievance and rights compliance generally. There was, however, common ground among study participants that the grievance process needed to be streamlined in order to be more responsive and timely (Social Science Research Center, 2013). The Old Dominion study, however, like much of the ombudsman program research, was a case study of a self-selected population. Of the studies we found in this area, like the

ombudsman research, almost all are without controlled interventions or control groups, and might have had sample bias issues.

Our review of available literature indicates that very little research has been conducted specifically in the area of securing rights and grievance processes for behavioral health populations. Studies in affiliated areas – for example in elder abuse, nursing home care, and the efficacy of the federally-sponsored long term ombudsman program – are more common, but also leave wide gaps in knowledge. With the exception of the Old Dominion University study, we found no other available studies in which grievance processes and rights of consumers were probed among such a large sample. However, the Old Dominion study was limited to examining general perceptions of Virginia’s grievance procedures across multiple sites. More specific evaluation designs of components of grievance processes are lacking, as are case-control approaches or experimental designs in which specific types of grievance related interventions could be examined. This is likely due to the difficulties of engaging both consumers and providers in this environment, and the complicated ethics involved with conducting research in this context.

We do recommend that further areas of study for a research agenda should include at least: 1) General satisfaction and perceptions with grievance processes from consumer, family member, advocate, and provider perspectives; 2) The use of new rights awareness and grievance process models and their outcomes; 3) The efficacy of training and enforcement procedures for provider and facility staff; 4) Training among volunteer residents or peer-support workers in the area of grievance procedures; 5) Health and/or quality of life indicators correlated to outcomes of grievance cases; and 6) Relationships between consumer and or institutional or program characteristics with grievance complaints.

## The Current Landscape

The PPC gathered information on this project from a number of sources. The PPC first conducted a scan of available and relevant resources online. This involved contacting national organizations active in the area of consumer rights, reviewing relevant materials, and interviewing key informants both for more information on the topic as well as leads to other resources. Sources for the literature review included peer-reviewed, academic literature, legal and professional journals, and state statutes.

The PPC reviewed materials from a variety of state government agencies which had a rights and grievances process or structure. Not all states appear to have a sufficiently strong consumer rights and grievance structure. Only a minority of states seem to have a well-established approach with available documentation and sufficient descriptive materials online and available for the public. A number of states were identified which had material on consumer rights, descriptions of their grievance protocols, or other applicable forms and guidance. A collection of those documents are included with this report (see Appendix). The PPC contacted several states and conducted interviews with leadership to learn more about their rights and grievance processes, and lessons learned. States with unique or representative features are outlined later in this report. A table listing national organizations and state entities contacted and interviewed is below (see Table 2).

**Table 2. Interview Contacts**

Bazon Center for Mental Health Law	National Advocacy Organization
Center for Practical Bioethics	National Advocacy Organization
NAMI (National Alliance on Mental Illness)	National Advocacy Organization
NDRN (National Disability Rights Network)	National Advocacy Organization
National Empowerment Center	National Advocacy Organization
Arizona Division of Behavioral Health Services, Bureau of Consumer Rights	State Agency
Maine Department of Health and Human Services	State Agency
Texas Department of State Health Services	State Agency
Vermont Department of Mental Health, Agency of Human Services	State Agency
Virginia Department of Behavioral Health and	State Agency

## Characteristics of Rights and Grievance Processes

### *General Legal Approaches and Current Nebraska Legal Structure*

States generally take a fundamentally similar legal approach towards consumer rights and grievances. All states we examined explicitly recognize consumer rights in their applicable laws, typically as part of a state's administrative code. Consumer rights generally cover areas ranging at a minimum of:

- Freedom from abuse, neglect, and exploitation.
- Right to be treated with dignity and respect.
- Right to actively participate in treatment/medication decision-making.
- Privacy and confidentiality rights.
- Communication and visitation rights.
- Informational rights (rights to information about facilities, services, evaluation, records, etc.)
- Activity rights (rights to participate in resident groups, recreational activities, etc.)
- Right to file grievance / complaint.

All states typically require that covered providers, whether they be day service/community service providers, or residential facilities, also have a grievance process for consumers to use. Thus, service providers must have an established policy in place to address consumer grievances.

Nebraska is currently in the process of revising its administrative code, and has a specific section in its code to address behavioral health services, title 206. Consumer rights are currently listed in 206 Nebraska Administrative Code 6-001 (Consumer Rights). Consumers have the right to freely voice complaints and grievances without fear of reprisal (206 NAC 6-002 Complaints), and every provider must have a written grievance policy in place. Additionally, all providers must provide contact information to consumers for the Nebraska Department of Health and Human Services, designated advocacy organization, Regional Behavioral Health Authority, Ombudsman's office, and other contacts if a consumer is not satisfied with a provider's grievance process (206 NAC 6-003 Consumer Grievances).

In addition to title 206, the administrative code also has licensing requirements for facilities and services that outline rights of residents/consumers as well as responsibilities as a condition of licensure. Those are found in 175 NAC 4.006.04 (assisted living facilities), 175 NAC 5-006.04 (adult day service), 175 NAC 6-006.05 (children’s day service), 175 NAC 7-006-04 (health clinics), 175 NAC 9-006.04 (hospitals), 175 NAC 12-006-05 (skilled nursing facilities), and 175 NAC 14-006-05 (home health care). It is important to recognize that these licensure requirements and enforcement processes are separate from those noted in title 206 for behavioral health services.

Additionally, Nebraska also maintains its child and protective services laws designed to address situations of abuse and neglect of vulnerable individuals in general, but with particular emphasis on those who are “substantially impaired and are unable to protect themselves from abuse, neglect, or exploitation.” The Nebraska Adult Protective Services Act is located at 28-348 to 28-387. It contains definitions for vulnerable adult (“any person eighteen years of age or older who has a substantial mental or functional impairment”) (Neb. Rev. Stat. 28-371), has categorical definitions for abuse (Neb. Rev. Stat. 28-351), neglect (Neb. Rev. Stat. 28-361.01) and exploitation (Neb. Rev. Stat. 28-358), and establishes processes for reporting and records keeping. This process, too, is separate from licensing enforcement and those consumer rights identified in title 206. Thus, like many states, Nebraska maintains somewhat of a patchwork approach to securing rights and the exercise of grievance processes.

#### *Variation in Administrative Structures and Features*

Although consumer rights and grievance processes are legally recognized across all states, there are differing levels of detail and administrative structures across states. We examined three states that have features worth noting in their rights and grievance systems because of either their representativeness or uniqueness: Arizona, Virginia, and Wisconsin. Brief overviews of those state approaches are located in the Appendix. Additionally, we located documentation from those and other

states, as well as the District of Columbia, that provide guidance or examples of relevant forms and materials in this area (See Appendix).

Wisconsin's **Client Rights Office** is charged with protecting rights of all clients receiving services for mental illness, developmental disabilities or substance abuse. The office has developed model guidance for **informally resolving grievances** at the provider level. Wisconsin also mandates that each provider/facility covered under their rights and grievances framework has a **designated Client Rights Specialist**, as well as a series of **training documents** for that Client Rights Specialist. The intention of the informal resolution guidance and training is to resolve as many grievances as possible as soon as possible without the need to initiate formal grievance processes.

If an informal process is not satisfactory, a consumer can utilize the **formal grievance process**, which is a 5-stage process of reporting and appeals from the provider level, to the county level, and finally to the state level. The formal process specifically identifies **position responsibilities and timelines** at each of the 5 stages for reporting, appeals, and documentation. It is important to note that the state, by law, maintains **original jurisdiction** to hear complaints and conduct investigations about **grievances related to grievance processes**. In other words, if a consumer believes that a service provider's grievance process is not fair or inadequate, that consumer can immediately contact the state Client Rights Office and bypass the provider.

Arizona maintains a **Bureau of Consumer Rights**, which is comprised of separate Customer Service, and Grievance and Appeals offices. The **Customer Service office** attempts to resolve issues informally. The Grievance and Appeals office houses the **official administrative grievance and appeals process** for the state. Thus, not unlike Wisconsin, Arizona has given intentional thought towards informal and formal procedures for complaints and grievances. The Bureau of Consumer Rights also contains an **Office of Human Rights**. The Office of Human Rights maintains a staff of 16 individuals whose responsibility is to directly help and advocate for the rights of the most vulnerable consumers,

particularly those with serious mental illnesses who are unable to function or advocate for themselves. There are seven **independent oversight bodies** in Arizona called human rights committees, one for each of the behavioral health regions in the state. The committees are created by statute and composed of volunteers who review the most serious cases from the state's official administrative grievance and appeals process. They are also able to conduct site visits. Arizona maintains a strong grievance and appeals **reporting process** for formal grievances. The state maintains a database and requires that all regional behavioral health networks enter reports of grievances into the database within 3 days of filing. The reporting is **mandated with subcontractors** of the regions that receive state funds for services via the state's contract with the regional networks. Additionally, Arizona is currently working on developing a rights and grievances **curriculum for peer-support** specialists in this area.

Virginia maintains a structure with some similarities to Arizona and Wisconsin. The Virginia **Office of Human Rights** oversees protection of all rights for those consumers in services or facilities covered by the Department of Behavioral Health and Developmental Services. Virginia requires that all covered providers have an identifiable staff member to assist consumers with filing grievances or resolving complaints. There is also a required **competency-based training** regarding rights and grievances that each designated staff member must complete on an annual basis. The Office also has its own **Human Rights Advocates**, who are state-employed staff whose responsibilities are to work with consumers and providers to facilitate the grievance process and resolve complaints, and generally serve to help consumers with a formal grievance process if consumers are not satisfied with the provider-based process. Like Arizona, Virginia maintains oversight bodies that are independent of both providers and the state called **human rights committees**. There is a statewide human rights committee and over 70 local human rights committees, which play a similar role in reviewing consumer grievances not satisfied through provider or formal processes, and review provider policies. All covered service providers in Virginia are affiliated with a designated local human rights committee. It should be

recognized that in interviews with those familiar with both the Arizona and Virginia human rights committee structures, it was noted that the committees play a valuable role as an independent review body. However, it was also stated that it can be difficult to maintain and operate human rights committees because of their volunteer nature, and there was a need to streamline and simplify the committees, their scope, and processes involved. Virginia also maintains a mandatory online reporting procedure for providers in regards to reporting grievances.

## **Recommendations**

Nebraska should consider the adoption of a uniform grievance process for consumers of behavioral health services. A statewide grievance process encourages uniform procedural requirements, accountability standards, data collection, and legislative oversight. A critical point should be made about the grievance structure in Nebraska. Currently, there is a great amount of deference towards providers of services to both create and administer their own grievance processes for consumers, so long as it meets a basic threshold of services required by the state. The benefit of this structure is that it allows providers to retain autonomy, police their own affairs, and it reduces regional or state bureaucracy and interference in day to day affairs of providers. The disadvantages of this structure are that it can discourage reporting by consumers out of fear of retaliation by provider staff, or lead to differing patterns of responsiveness among providers. In short, this leads to a situation where the state-based rights of consumers, including the right to grieve, are largely enforced by individual providers without a guarantee of accountability, or way to centrally monitor grievances and resolutions. We believe that both grievance processes at the provider level, and an accompanying grievance structure at a regional and state level, must be considered together to adequately enforce consumer rights, and that stronger state involvement is necessary. At the same time, it should be recognized that more governmental involvement can also mean less responsiveness, greater bureaucracy, and more complexity for

consumers. However, structural changes are necessary to provide the accountability and enforcement that is lacking in the current status quo.

In our review of state grievance approaches (above), we noted several states that have noteworthy grievance process structures in place with significant levels of state oversight and/or involvement. In the interviews we conducted, representatives from those states cautioned how extensive procedures – though well intentioned – can lead to delays for consumers within the grievance and appeals process. Additional consideration should be given to the fact that Nebraska’s behavioral health system is based on a regional approach where the behavioral health regions work in partnership with the state for delivery of services. This model is, however, not unlike several other states which also have regional structures for behavioral health services, including Arizona, which also has a strong, state-centered approach towards enforcement of consumer grievances. We sought to identify principles that would reflect a balance between strengthening consumer grievance processes with uniform oversight, while maintaining as an important value a desire to have a streamlined and understandable process and structure within a regional framework. These recommendations serve as general guideposts that should inform more detailed review and discussion.

#### *Recommended Model Grievance Process and Components*

- **Recommendation 1:** All covered service providers/facilities must have a written grievance process and forms available. Written documentation should be in plain English and the equivalent in second languages. All provider procedures and forms must be reviewed for adequacy at the state level for uniform requirements. At a minimum, the uniform requirements must both include and communicate the following (as referred to or in addition to other items outlined below):
  - Options for informal resolution of grievances, and appropriate contact information;

- Description of what constitutes a grievance (any potential violation of a consumer's rights);
- Instructions for initiating a formal grievance, with whom, and concise description of all steps involved, including process for appeal of a decision;
- The name and contact information of the designated staff member(s) for assistance with filing a grievance, and options and contact information to obtain outside assistance;
- Timeline and time limits for all steps and resolution of a grievance, and written notification at all steps;
- Instructions and guidelines for timely, confidential, and fair investigation of grievances (e.g. review of documentation, interviewing witnesses, etc.);
- Decisions in writing, and notification of appeal rights;
- Confidentiality and privacy structure for the grievance filing and subsequent investigation activities;
- Confidential records keeping process so all formal grievances and outcomes are kept with the provider, which the grievor has a right to review, and provided to state authorities;
- Procedures for assisting those with severe mental illnesses in all stages of the grievance and appeals process;
- Procedures for expedited review of grievances if they involve allegations of abuse or neglect, or other serious allegations involving one's life or health.
- Requirements for clearly posting necessary grievance process information in public areas.

- **Recommendation 2:** All covered service providers/facilities must have a designated staff member(s) to assist consumers/residents with filing grievances, administer the grievance program, conduct trainings, and report grievance information to the state. The designated person must receive state approved training, renewed on a regular basis.
- **Recommendation 3:** If a grievance cannot be resolved informally, a formal grievance can be made, orally or in writing, within a designated time of its occurrence, to the provider's chief administrator (level 1). A level 2 appeal can be made to the regional administrator, and final appeal (level 3) made to the state. Written receipt of notice and resolution must be issued to the consumer within a designated period of time. Timeliness should be emphasized in properly investigating and responding to grievances.
- **Recommendation 4:** The State should retain original jurisdiction to investigate grievances about grievance processes or retaliation, or grievances involving allegations of abuse or neglect. These grievances should bypass the provider's grievance process and be filed directly with regional authorities.
- **Recommendation 5:** A consumer rights pamphlet in plain English (and multiple languages) must be made available to all consumers and family members at the earliest convenient contact point, and be visibly and clearly posted in all common spaces. It must also contain contact information for regional and state contacts, as well as for designated outside advocacy groups.
- **Recommendation 6:** An online portal should be created for all covered providers to mandatorily report filed grievances and outcomes to the state within a designated time. This data should be

monitored and analyzed on a regular (quarterly and annually basis) for trends. Data should be made publicly available in aggregated, non-identifying forms.

- **Recommendation 7:** An independent, voluntary human rights body should be considered for each region and the state level, composed of trained and qualified consumers, family members, mental health professionals, and others, to review cases of egregious grievances, conduct audits, and make recommendations to providers and the state. Care should be taken that these bodies serve the role of a review body independent of regions, state, and providers, but that they also function in a streamlined and focused fashion.
- **Recommendation 8:** Develop a defined administrative hearing process for state level review of grievances (level 3) and appeals that meets procedural and substantive due process requirements which accounts for potential conflicts of interest. A process should also be developed for appeal from agency level decisions to the applicable county or district court if an individual is not satisfied with the final agency level review of their grievance.
- **Recommendation 9:** Develop and administer trainings for consumers and consumer peer support specialists in rights and grievance procedures. Peer support specialists could serve a potentially important role in advocating and educating for consumer rights and assisting consumers with navigating grievance processes. An independent consumer specialist within each behavioral health region could serve an important role as a designated trainer in this area. Additionally, more general trainings in civil and human rights should be administered for interested consumers, consumer peer specialists, family, provider staff, and others.

- **Recommendation 10:** The State should develop a systematic forum to receive and address consumer, family and public input about system-wide issues and grievances related to availability and access to behavioral health services.
- **Recommendation 11:** The State should conduct an independent study assessing the need for further advocacy resources across the state, particularly in rural portions, and develop a plan to address existing gaps.

We suggest as a potential next step that these recommendations be considered, discussed, and refined at a more detailed level by a qualified body of consumers, family members, advocacy organizations, providers, and policy makers. All of these recommendations are based on approaches that have been or are being employed in other states; thus, they serve as viable models that Nebraska can learn from and apply. Nebraska's regional behavioral health system may facilitate adoption of these recommendations. For instance, elements of these recommendations could be piloted in a single region, and then reviewed at a later date.

Additionally, should Nebraska employ such mechanisms, the opportunity should be used to conduct research or evaluation on these interventions. As discussed earlier, there is a significant dearth in research on this issue, and developing an evidentiary basis for the effectiveness of such approaches is critical for advancing a research and practice agenda in consumer rights and grievances.

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