Maximizing Seniors' Autonomy and Independence in the Least Restrictive Setting

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Kathy Pryor, Virginia Poverty Law Center[1]

Less Restrictive Alternatives to Guardianship[2]

I. Introduction

- May not be a question of whether or not to intervene at all but what is the least restrictive intervention which will safeguard the individual while still maximizing the independence and autonomy of the elderly person.

- Alternatives to guardianship are "various legal tools, social services and government programs that may delay or prevent the appointment of a guardian for a person who is not capable of making decisions on his or her own behalf." Stiegel, L. "Alternatives to Guardianship," ABA Commission on Legal Problems of the Elderly (1992).

- May need one or a combination of legal tools and services to adequately resolve problem or may need different tools/services at different times.

- Different approaches to alternatives: (1) financial vs. health care or living arrangements; (2) planned vs. unplanned—whether individual has planned for incapacity in advance by signing various documents, designating decision makers, or whether there is the need to respond to already existing functional limitations without direction from the individual; (3) delaying vs. substituting for guardianship; (4) types of limitations for which assistance is required.

- Factors to consider in analyzing various alternatives: (1) capacity; (2) risk; (3) complexity; and (4) availability of an adequate support system. K. Wilber, "Rethinking Alternatives," (1995). The greater the incapacity, risk, and complexity and the more limited the support system, the more likely guardianship may be the best alternative—but if all these factors are not present, alternatives to guardianship may be adequate.

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[1] Kathy Pryor, kathy@vplc.org, Virginia Poverty Law Center, 700 East Franklin Street, Suite 14T1, Richmond, VA 23219; (804) 782-9430.
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- Often the family or the elderly person is first seeking an attorney when it is too late to plan ahead for incapacity because the elderly person already lacks the capacity (to appreciate the nature of her act) to understand and sign a power of attorney or other legal document.

II. Person Needs Medical Treatment But Cannot Consent

A. Living Will, Health Care Power of Attorney, Advance Medical Directive

1. Living Will is a written statement made by a competent adult "authorizing the providing, withholding, or withdrawal of life-prolonging procedures in the event such person should have a terminal condition." Va. Code § 54.1-2983. Limited to end of life decisions.

2. Health Care Power of Attorney (or 'health care proxy' or 'medical power of attorney') is a statement by a competent adult appointing an agent to make health care decisions in the event the declarant is unable to make an informed decision.

3. Advance Medical Directive combines a living will and a statement appointing an agent into one document by which the person can direct that a specific procedure be provided or withheld and/or appoint an agent to make health care decisions as specified if the declarant is determined to be incapable of making an informed decision. Health Care Decisions Act, Va. Code §§ 54.1-2981 through 54.1-2993. An optional form is provided at Va. Code § 54.1-2984. Document to be signed in presence of two witnesses. A competent adult diagnosed as having a terminal condition can make an oral advance directive in the presence of the attending physician and 2 witnesses. § 54.1-2983. Determination of "incapable of making an informed decision" (inability, because of mental illness, mental retardation or other mental or physical disorder which precludes communication or impairs judgment, to understand the nature, extent or probable consequences of the proposed medical decision or to make a rational evaluation of the risks and benefits of alternatives to that decision) is made by attending physician and a second physician or licensed clinical psychologist after a personal examination and certified in writing. AMD can be revoked at any time with a signed, dated writing, physical cancellation or destruction by the declarant or at his direction, or by oral expression of intent to revoke.

4. Advance Health Care Directive Registry authorized by 2008 General Assembly—for the Department of Health to make available and maintain a secure online central registry for advance directives which would be accessible to health care providers. §§ 54.1-2994 and -2995.

5. Probably more important to encourage communication between the principal and agent to be sure the agent knows the wishes of the principal and will follow those wishes than to set out details about what treatment the principal would want or not want in the AMD.

B. Health Care Consent Procedure in Absence of Advance Directive

1. Va. Code § 54.1-2986 provides that when an attending physician has determined that an individual is incapable of making an informed decision about the provision, withholding or withdrawing of specific medical treatment, and there is no advance directive or there is a directive which does not indicate his wishes as to this treatment and no agent is appointed, the treatment may be authorized by those listed in order of priority. The decision is to be made on the basis of the patient's religious beliefs, basic values and expressed preferences, or if not known, on the basis of the patient's best interests.

2. The order of priority is a guardian or committee, patient's spouse, adult child(ren), parent, adult sibling, other relatives in descending order of blood relationship. If there is disagreement by persons in the same class, the doctor may rely on the authorization of the majority of those reasonably available in that class.

3. Va. Code § 54.1-2970 provides for treatment of physical injury or illness for an individual who is a patient or resident of a hospital or facility operated by DMHMRSAS or a consumer receiving case management services from a CSB or behavioral health authority and who is incapable of giving informed consent because of mental illness or mental retardation if (1) no legally authorized guardian or committee is available to give consent; (2) a reasonable effort to advise a parent or other next of kin of the need for the treatment has been made; (3) no reasonable objection is raised by or on behalf of the alleged incapacitated person; (4) two physicians, or if dental treatment, two dentists or one dentist and one physician, state in writing that they have made a good faith effort to explain the necessary treatment and have probable cause to believe the individual is incapacitated and unable to consent by reason of mental illness or mental retardation, and that delay in treatment might adversely affect recovery. This section does not apply to treatment of the individual's mental, emotional or psychological condition, but indicates that would be governed by regulations promulgated by DMHMRSAS. See also §§ 37.2-400.B. and 37.2-401.

C. Five Wishes

1. Written in lay language and includes not only medical but also person, emotional and spiritual wishes of a seriously ill person: "the person I want to make care decisions for me when I can't"; "the kind of medical

treatment I want or don't want"; "how comfortable I want to be"; "how I want people to treat me"; "what I want my loved ones to know". Form produced by Aging with Dignity, Tallahassee FL, www.agingwithdignity.org. See also NCCNHR's tool for person-directed care: "My Personal Directions for Quality Living" at http://www.nccnhr.org/uploads/QualLivingPersonalDirs.pdf.

III. Litigation Against or By the Disabled Person

A. Appointment of a Guardian Ad Litem solely for the purpose of representing the best interests of the individual in the litigation and making decisions for pursuit of case.

IV. Problem Involves a Family Dispute—Use of Mediation

A. Conflict among siblings on what to do about Mom or conflict between adult children and the elderly parent.

B. Philosophical Differences between maximizing protection and maximizing independence—questions about whether or not Mom is able to make her own decisions; whether a less restrictive alternative is available; whether guardian's powers should be limited; whether someone other than the petitioner should be named guardian if guardianship is necessary.

C. Advantages of Mediation

1. Confidential, private and less intimidating than courtroom setting.
2. Allows consideration of ways to reduce risk to safety and health but retain autonomy and independence.
3. Mutually acceptable solution with help of neutral third party---win-win solution.
4. Better preserves family relationships than contested court battle.
5. May be less costly and time-consuming and less emotional cost.
6. May come up with more creative solutions to solve problems.

V. Person Needs Help with Financial Issues

A. Durable Power of Attorney

B. Representative Payee for federal benefits—Social Security, SSI, Veterans, Civil Service and Railroad Retirement.

1. Authority of rep payee is limited to handling only the public benefit, not to managing any other accounts or assets.

2. Is simple and inexpensive; does not require finding of incapacity and allows the person to continue to make decisions in other arenas.

3. Some reporting requirements but limited oversight or safeguards so misuse may not be detected.

C. Joint Bank Account—easy and inexpensive to establish and enables the joint account holder to manage the income of the incapacitated person. But risky since the joint owner could withdraw all the money and account could be subject to creditors of the co-owner.

D. Direct Deposit of Benefits and Automatic Bill Payment

1. Allows individual to have bills paid automatically on time every month on the date selected by the individual and avoid late or missed payments; reduced risk of termination of services.

2. Individual must authorize automatic transfer of payment from his account to the billing entity so may not be option for someone unable to do that.

E. Money Management or Bill Paying Services

1. Help paying bills, balancing checkbook, etc. through an individual or organization.

2. Need to be sure provider has system of cash controls to avoid mismanagement and is bonded and insured to protect client from theft or loss.

3. Useful for those without a POA and without sufficient assets to warrant a trust; individual remains in control and no determination of incapacity.

4. Disadvantages: lack of oversight, potential for abuse; not available in all communities; person must have sufficient capacity to direct the provider.

F. Third Party Notification

1. By Utilities—allowing customer to designate a third party to be notified if bills are not paid on time.

2. By Landlord: Va. Code 55-248.9:1.B allows a tenant to designate a third party to receive duplicate copies of summons and written notices from the landlord and requires the landlord to send such notices to the designated third party at the same time as they are sent to the tenant. The hope is that the designated third party could intervene—to make sure the rent is paid or to help resolve other problems—before an unlawful detainer is issued and the tenant is faced with possible eviction.

G. Trusts—a trust is a legally binding arrangement through which a grantor transfers money or property to a trustee who manages the trust property for the benefit of the grantor or other named beneficiaries according to the instructions in the trust document. The trustee has a fiduciary duty to manage the assets in a prudent manner.

1. Advantages: can provide professional management of funds in case grantor becomes incapacitated; trustee can manage funds for persons with disabilities and contract for care or services; may have tax and probate advantages; high acceptance in business and professional community.

2. Disadvantages: costly so only appropriate if there are substantial assets involved; will adversely affect Medicaid eligibility for long term care (either as a countable resource or as an improper transfer) unless created in a specific way.

H. National Do Not Call Registry (https://www.donotcall.gov/default.aspx); write Mail Preference Service (Mail Preference Center, Direct Marketing Association, Box 643, Carmel, NY 10512) to remove name.

VI. Person Is Living in An Unsafe Environment

A. External or Internal Safety Concerns may necessitate a move to a more secure environment.

1. Community residential care or congregate housing
2. Adult Foster Care
3. Assisted Living
4. Nursing Home
5. Continuing Care Retirement Communities (CCRCs)

B. Internal Safety Concerns may indicate need for additional assessment and/or services or possibly a move to a setting with more supervision.

1. Having falls—get fall assessment and make changes in living arrangement
2. Fire hazard
3. Hoarding
4. Not eating properly
5. Not taking medications properly
6. Isolation

VII. Person Needs Help with Activities of Daily Living or Supervision to Remain in Home

A. Generally call your local Area Agency on Aging for assistance with what services are available in your community

B. Community Based Care Waivers through Medicaid

C. Home Health Services

D. Case management
E. Adult Day Care
F. Respite Care
G. Meals on Wheels
H. Personal Emergency Response System (PERS)
I. Medication management
J. Environmental Modifications or Assistive Technology to enable person to stay in home
K. Senior Centers and Meals Programs
L. Companion and housekeeping services
M. Telephone reassurance programs
N. Home visitors and pets on wheels
O. Daily checks by mail carriers
P. Transportation services

Less Restrictive Alternatives to Nursing Homes

I. Olmstead v. L.C., 527 U.S. 581 (1999).

The U. S. Supreme Court ruled that the Americans with Disabilities Act (42 U.S.C. § 12131 et. seq) required state and local governments to serve people with mental disabilities in the most integrated setting possible unless the defendant can prove that the requested relief would alter the essential nature of the program or impose an undue burden or hardship in light of the overall program—a fundamental alteration of a service or program.

II. Reasonable Accommodations under the Fair Housing Act or Americans with Disabilities Act

A. Tenant has initial burden of requesting an accommodation, establishing the existence of a disability and demonstrating that the accommodation may be necessary to afford equal opportunity. The burden then shifts to the landlord to establish that an undue burden or fundamental alteration would be caused by granting the accommodation. Otherwise, if can't show a fundamental alteration, the accommodation should be considered reasonable and granted.

1. A person with a disability is defined as an individual with a physical or mental impairment that substantially limits one or more major life activities; an individual regarded as having such an impairment or an individual with a record of having such an impairment. 42 U.S.C. § 3602(h). A "major life activity" is an activity of central importance to daily life, including but not limited to seeing, hearing, walking, breathing, performing manual tasks, caring for one's self, learning, speaking. "Substantially limits" means the limitation is significant or to a large degree.

2. The Fair Housing Act defines "dwelling" broadly as "any building, structure, or portion thereof which is occupied as, or designed or intended for occupancy as, a residence by one or more families…", 42 U.S.C. § 3602(b). This has been interpreted to apply to

retirement communities (Weinstein v. Cherry Oaks Ret. Cmty., 917 P.2d 336 (Colo. Ct. App. 1996); to condominiums (Gittleman v. Woodhaven Condo. Ass'n, Inc., 972 F. Supp. 894 (D.N.J. 1997); and to nursing homes (Hovsons, Inc. v. Township of Brick, 89 F.3d 1096, 1102 (3d Cir. 1996).

3. Examples of reasonable accommodations: live-in aide, service animal, notices in large print or audiotape, designated parking spot, accessible unit on first floor.

4. Failure to allow a reasonable accommodation may be enforced by (1) complaint to HUD; (2) DOJ if there is a pattern and practice of discrimination; (3) litigation in state or federal court. Can result in monetary settlement, allowance of the reasonable accommodation, restriction on PHA's use of funds.

5. A request for a reasonable accommodation may also serve as a defense to eviction. See, e.g., Josephinium Associates v. Kahli, 45 P.3d 627 (Wash. App. 2002)(see fn. 26 for a listing of state cases supporting the idea that unlawful discrimination can constitute a defense to eviction); Douglas v. Kriegsfeld Corp., 884 A.2d 1109 (D.C. 2005).

III. Community Based Care Waivers

A. Virginia has the following waivers: Elderly or Disabled with Consumer-Direction, AIDS, Mental Retardation, Technology-Assisted Individuals, Day Support, Alzheimer's Assisted Living (only for those on Auxiliary Grant and living in assisted living facility), Individual and Family Developmental Disabilities Support.

B. Waivered covered services for elderly and disabled individuals include personal care, respite care, adult day health services, personal emergency response system (PERS).

C. Waivered covered services for those on the MR waiver include personal care, respite care, private duty nursing services, environmental modifications, residential support services, personal assistance services, assistive technology services, day support services, supported employment services, therapeutic consultation.

D. Effective September 1, 2006, for all but those on the AIDS waiver (who are allowed to keep 300% of the SSI level), the personal maintenance allowance increased from 100% to 165% of the SSI level, or, in 2009, to $1112.10 per month. This will enable disabled people on waivers to retain more of their own income and will enable more disabled people to remain in the community because they will now have enough money to pay the rent or mortgage and other expenses.

E. Suit in New York State challenging, on ADA grounds, actions by the Departments of Health and Social Services to terminate 24 hour home care services under Medicaid as not being "cost-effective," which action would have resulted in nursing home placement for the affected individuals. The court vacated the actions to discontinue 24-

hour personal care services and remanded for the agencies to reassess their actions in light of the requirements under the ADA. The court held that Medicaid would have to show that accommodating individuals who otherwise qualify for 24 hour home care would result in a fundamental alteration in the Medicaid program; otherwise, it must provide services in the most integrated setting appropriate to the needs of the individual. Rubin v. DeBuono, Commissioner of NY State Dept. of Health, No. 402767/98 (Feb. 25, 2000).

IV. Money Follows the Person ("MFP")

A program to enable transitions from nursing home to the community. Instead of Medicaid money paying only for nursing home care, the funds are shifted to provide services in the community to enable disabled persons to live in the community.

A. CMS is funding MFP grants, with the State Medicaid agency as the lead applicant, to "eliminate barriers or mechanisms" in state law, Medicaid plans, state budget. MFP funds can be used to promote availability, affordability and accessibility of housing for disabled individuals through funds for new construction or conversion of housing for the disabled; through rental subsidies, temporary bridge programs and homeownership options, and through home modifications and universal design; MFP funds can also be used to furnish an apartment, pay security deposits and utility set-up fees, cleaning fees prior to occupancy.

B. Virginia received a MFP grant in May 2007 and is implementing a program which became effective July 1, 2008. Over the 4-year demonstration period, Virginia intends to move over 1,000 people out of nursing homes, intermediate care facilities for persons with intellectual disabilities, and long-stay hospitals.

C. To participate in Virginia's MFP program, an individual must have lived for at least 6 consecutive months in a nursing facility, ICF/MR, or long-stay hospital; must be a resident of Virginia; must be Medicaid eligible for at least one month at the time of discharge; qualify for one of five waiver programs (Elderly or Disabled with Consumer Direction; Individual and Family Developmental Disabilities Support Waiver; HIV/Aids Waiver; Mental Retardation Waiver; Technology Assisted Waiver); and be moving to a qualified residence (a home that the individual or his family owns; an apartment with an individual lease; or a residence in a community based residential setting in which no more than 4 unrelated individuals reside).

D. Individuals participating in Virginia's MFP program will have either a transition coordinator or a case manager to assist with all the details of making the transition. They can qualify for up to $5000 in environmental modifications with the possibility of supplemental home modifications if needed; life-time financial assistance of up to $5,000 with up-front, essential household expenses at the time of transition; assistive technology; Personal Emergency Response System and Personal Emergency Response System medication monitoring; use of 2-1-1 Virginia as the Tier 3 emergency back up support.

E. Virginia's MFP program is designed to rebalance Virginia's long term care support system by providing individuals with more informed choices and options about where they live and receive services; to transition those who choose to live in the community from the institutions where they currently reside; and to promote quality person-centered care which is appropriate and based on individual needs.

F. The flip side of getting people out of nursing homes in this way is the idea of making sure disabled individuals and their families are aware of community-based options before they go into a nursing home and that there are effective procedures in place to ensure that available community-based options are discussed and considered prior to admission to a nursing home. Vermont's Choice for Care Medicaid waiver allows them to pool funds for nursing home and community care. A team of nurses visits elderly persons who are too frail to live at home or who have been admitted to a hospital to assess the level of care needed and the patient's preferences and then to arrange home services if the person prefers to stay at home.

V. Mainstream Housing Vouchers

For persons with disabilities to receive a subsidy to enable them to pay rent and reside in the community in private housing market. These vouchers are supposed to be issued and then reissued only to persons with disabilities, but this doesn't always happen.

A. Under the Housing Choice Voucher program, a PHA may give preference in admission to applicants with disabilities, but may not give a preference for admission of persons with a specific disability. 24 CFR § 982.207(b)(3).

B. Although normally a PHA does not approve leasing of a unit from a relative, it can do so if approving the unit would provide a reasonable accommodation for a person with a disability. 24 CFR §982.306(d). However, this may not apply to shared housing where the relative owner lives in the unit. 24 CFR § 982.615(b)(3).

VI. "Independent Living" Requirements in Rental Housing, Assisted Living Facilities and Continuing Care Retirement Communities and the Right to Age in Place[3]

A. "No Inquiry" Rule regarding disability under the Fair Housing Act

1. The broad definition of "dwelling" under the FHA, 42 U.S.C. § 3602(b) suggests that it applies to all types of housing. Courts have held that the FHA applies to retirement communities (<u>Weinstein v. Cherry Oaks Ret. Cmty</u>., 917 P.2d 336 (Colo. Ct. App. 1996), to condominiums (<u>Gittelman v. Woodhaven Condo. Ass'n, Inc.,</u> 972 F. Supp. 894 (D.N.J. 1997), to apartment complexes, coops, assisted

[3] Much of the material in this section is credited to Michael Allen and the Bazelon Center for Mental Health Law., in particular their publications "The Illegality of 'Independent Living' Requirements in Rental Housing, Assisted Living Centers and Continuing Care Retirement Communities" and "Preserving Elders' Housing Rights" by Michael Allen and Susan Ann Silverstein.

living facilities, and to nursing homes (Hovsons, Inc. v. Township of Brick, 89 F.3d 1096 (3d Cir. 1996).

2. The Fair Housing Act prohibits inquiries into the "nature or severity" of a disability. 24 CFR § 100.202(c).

3. A housing provider must base decisions on whether the applicant can meet the tenancy obligations—pay the rent, comply with reasonable rules, such as not disturbing others and not damaging the property. A tenant can meet the obligations of tenancy with or without assistance—e.g. can rely on family members, social services workers, paid service providers.

4. A housing authority can verify a person's disability only to the extent necessary to ensure applicant is able to meet the requirements of tenancy, is qualified for the housing for which he is applying, that he is entitled to any claimed preference, is not a current abuser or addict or a controlled substance, or to demonstrate the need for a requested accommodation.

B. "Independent Living" Requirements

1. There have been a series of cases interpreting the Fair Housing Act's ban on handicap discrimination to prohibit housing providers from imposing a requirement that tenants be capable of "independent living."

2. See, e.g., Cason v. Rochester Housing Authority, 748 F. Supp. 1002 (W.D.N.Y. 1990); Niederhauser v. Independence Square Housing, No. C96-20504, FH-FL Rep. 16,305 (N.D. Cal. Aug. 27, 1998); Jainniney v. Maximum Independent Living, Case. No. 00CV0879 (N.D. Ohio Feb. 9, 2001)(although § 811 subsidy authorized the defendant to favor those with physical disability over others, it did not authorize owners to exclude those with physical disabilities who might have other disabilities as well or to discriminate on the basis of the ability to live independently; independent living is not a proper admissions criteria for § 811 housing.).

3. In Cason, 3 disabled individuals brought a claim against the public housing authority after it rejected their applications because they did not meet the "ability to live independently" eligibility requirement (one was a younger schizophrenic woman; the other two were elderly women with physical handicaps). Cason was denied because of her need to use a wheelchair, because she was incontinent and used adult diapers, and because she needed 10 hours of daily aide service. The PHA complained that it lacked staff to provide support services to tenants, but the plaintiffs stressed they were not seeking supportive services from the PHA, but obtained necessary supports from Medicaid or other sources. The court noted that a tenant who can meet the objective requirements of tenancy cannot be denied housing because she receives medical assistance or other aid. The court held that the 'ability to live independently' tenant selection criterion violated federal law

because it had the effect of discriminating against disabled applicants and ruled that such a criterion could not be used in the tenant selection process. Cason resulted in HUD revising its public housing occupancy policies to clarify that a PHA cannot use "independent living" eligibility criteria. Other cases under the FHA have resulted in judicial orders or consent decrees which required the provider to eliminate the independent living requirement.

4. The Justice Department brought a "pattern or practice" complaint against a retirement community in United States v. Resurrection Retirement Community, Inc., No. 02-CV-7453 (N.D. Ill. Oct. 16, 2002), alleging that the community violated the FHA by discouraging prospective residents who used wheelchairs and by requiring applicants to submit medical assessments as a condition of residency. The case resulted in a consent decree including monetary damages and penalties and an agreement to rescind the independent living and medical exam policies.

5. These cases have been in the senior rental housing arena and it is not clear whether they would be applicable to independent living requirements in an assisted living facility (ALF) or continuing care retirement community (CCRC). One issue would be licensing and the level of care and the degree to which facilities with a medical component need to ask about the resident's health and disability status in order to comply with state licensing requirements.

C. Limitations During Tenancy

1. One court has held that, under the FHA, residents can't be prohibited from using wheelchairs, walkers or other equipment in common areas. Weinstein v. Cherry Oaks Ret. Cmty., 917 P.2d 336 (Colo. Ct. App. 1996).

2. However, another court held that a retirement community had a legitimate safety interest in restricting use of motorized carts in common areas during periods of peak use. United States v. Hillhaven Corp., 960 F. Supp. 259 (D. Utah 1997).

3. Requiring users of motorized wheelchairs to obtain liability insurance as a condition of continued residency when others were not required to obtain such insurance has been found to be a violation of the FHA's prohibition against discrimination in the "terms, conditions, or privileges" of tenancy. Sec'y, HUD v. Country Manor Apartments, HUDALJ No. 05-98-1649-8, 2001 WL 1132715 (ALJ Sept. 20, 2001); 42 U.S.C. § 3604(f)(2)(2001).

D. Refusal to Grant Reasonable Accommodations

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1. See § II. above

2. The obligation to provide reasonable accommodations applies at all stages of the housing relationship.

E. Forced Transfers

1. In some cases, the independent living criterion has been used to try to force residents to move from their apartment to a higher level of care because of the facility's determination that the resident was no longer able to live independently.

2. In Symons v. City of Sanibel (M.D. Fla. 2003), an apartment resident protested the apartment manager's attempt to evict him based upon a decision that he could no longer live independently. His FHA challenge resulted in a settlement allowing him to remain in place and requiring the apartment to eliminate from its tenancy criteria any reference to a resident's ability to live independently.

3. An 80 year old resident of a retirement community who had been diagnosed with ALS sued the CCRC under the ADA and FHA when the CCRC attempted to force her to move to the nursing home level of the facility or to vacate altogether, based on its policy prohibiting long-term use of personal care attendants in its apartments and giving the CCRC unilateral authority to determine where residents should be placed. Notably, the resident had hired the personal care assistants with her own money and had not sought any additional services from the CCRC. Bell v. Bishop Gadsden Retirement Community was filed in federal court in S.C., alleging various violations of the FHA and ADA, including failure to reasonably accommodate her disabilities by allowing her to have personal care attendants, unlawful inquiries into the nature and severity of her disabilities, inappropriate requirements that she prove her ability to move around or perform other tasks independently, and the attempted involuntary transfer to a more restrictive living situation based upon her disability. Although the resident died before trial, the case settled with the facility agreeing to allow residents to use personal assistants and assistive devices such as motorized wheelchairs and also paid the resident's attorney's fees. The settlement allowed other residents to ask for more flexible terms than those to which the resident's family had agreed. This was apparently the first court case in which an "independent living" requirement in the CCRC context has been challenged, but, of course, did not result in a holding due to the settlement.

Maximizing Rights and Autonomy in the Nursing Home Setting

I. Issues at Time of Admission

A. Responsible Party or Third Party Guarantee Provision as Condition of Admission

i. Federal and state law prohibit a facility from requiring a third party guarantee of payment as a condition of admission, expedited admission, or continued stay in the

facility. 42 U.S.C. § 1396r(c)(5)(A)(ii); 42 CFR § 483.12(d)(2); Va. Code § 32.1-138.3.

ii. A facility can require a person with legal access to the resident's income or resources to sign a contract to provide payment from the resident's income or resources, without incurring personal financial liability except for breach of the duty to provide payment from the resident's income or resources. 42 CFR § 483.12(d)(2); Va. Code § 32.1-138.3.

B. Indemnification provisions/Negotiated risk/ Waiver of Liability Provisions

i. Provisions which attempt to limit the nursing home's liability or to get families to provide private duty personnel if they don't think the resident is getting adequate care.

ii. Sample language such as the services of the facility are "not designed to somehow protect the resident from everyday, normal risks and responsibilities of living, including…situations such as falling, choking and weight loss and/or dehydration." Or "The Parties specifically understand and agree that the quality of care provided by this facility is limited by staffing levels provided and quality of staff. Therefore if the Resident and/or responsible party desire to reduce the risk of injury associated with staffing provided by the facility, they shall arrange for and provide supplemental private duty nursing….If the resident or responsible party choose not to provide supplemental private duty nursing, the resident and responsible party agree to indemnify and hold facility harmless for any injury or harm that could have been avoided had supplemental private duty nursing been provided by the resident or responsible party."

iii. Nursing facilities are required by federal law to have sufficient staff to provide the necessary care and services for each resident to "attain or maintain the highest practicable physical, mental, and psychosocial well-being," 42 CFR §§ 483.25, 483.30. A facility cannot get out of its legal obligations by shifting the responsibility of providing adequate care onto the resident and his family.

C. Arbitration Agreements

i. Lots of litigation nationwide around arbitration agreements in nursing home admissions contracts. In deciding whether

to enforce the arbitration agreement, courts have looked at such issues as whether the signatory had authority to sign; whether the resident signatory was competent; whether there is either procedural or substantive unconscionability.

ii. Advocates believe arbitration is generally not good for nursing home residents—more expensive because have to pay arbitrator's costs and filing fees; tend to be lower awards for residents than in court; arbitrators may have incentive to rule for nursing homes to get repeat business; resident gives up right to jury trial and to discovery; need to hold facilities accountable for bad care and better that this be done in an open legal process, with discovery of corporate practices available.

iii. Fairness in Nursing Home Arbitration Act (H.R. 1237 and S. 512) is now before Congress. It would invalidate mandatory pre-dispute arbitration agreements in nursing home and assisted living contracts.

D. No Discrimination against Medicaid-Eligible Residents in Policies, Practices and Services, but not necessarily in Admissions (42 U.S.C. § 1396r(c)(4) and (c)(5)(B); 42 CFR § 483.12(c) and (d)(4).

i. A nursing facility must establish and maintain identical policies and practices regarding transfer, discharge and provision of services under the State plan for all individuals regardless of source of payment. 42 U.S.C. § 1396r(c)(4); 42 CFR § 483.12(c)(1).

ii. Facility may not charge, solicit, accept or receive any gift, donation or other consideration as a precondition of admission, expedited admission or continued stay from a person eligible for Medicaid or require a resident or potential resident to waive rights to Medicaid or Medicare. 42 U.S.C. § 1396r(c)(5)(A)(i) and (iii); 42 CFR § 483.12(d)(3) and (d)(1)(i).

iii. But it is <u>not</u> clear that federal law prohibits a facility from choosing a private pay patient over a Medicaid patient in admissions. "No preemption of stricter standards. Subparagraph (A) shall not be construed as preventing States or political subdivisions therein from prohibiting, under State or local law, the discrimination against individuals who are entitled to medical assistance under the State plan with respect to admissions practices of nursing

facilities." 42 U.S.C. § 1396r(c)(5)(B). "States or political subdivisions may apply stricter admissions standards under State or local laws than are specified in this section, to prohibit discrimination against individuals entitled to Medicaid." 42 CFR § 483.12(d)(4).

II. Residents' Rights/ Care Issues

A. Care Planning

1. Local long term care ombudsman as a good resource.

2. A nursing home must complete a full assessment of a resident's condition within 14 days of admission, at least once every 12 months thereafter, and within 14 days after a significant change in the resident's physical or mental condition. 42 CFR § 483.20(b)(2).

3. The facility must develop a comprehensive care plan for each resident to identify services necessary to "attain or maintain the resident's highest practicable physical, mental, and psychosocial well-being." 42 CFR § 483.20(k) and 42 CFR § 483.25.

   i. The care plan should be developed by an interdisciplinary team, including the attending physician, registered nurse with responsibility for the resident, other staff and should include the resident and the resident's family or legal representative. 42 CFR § 483.20(k)(2)(ii).

   ii.This is a good opportunity for the resident and family to have input into the resident's care so as to individualize his care to meet his needs and preferences. It can also be an effective way to deal with facility complaints regarding resident behaviors and to seek other approaches to the resident that might lessen adverse behaviors. If the resident is threatened with possible transfer or discharge due to behavior issues, seeking a care planning meeting might be a way to try to address the behavior problems in a constructive way and avoid initiation of discharge proceedings by the facility.

B. Bad or Inadequate Care Problems—ombudsman as resource to try to resolve; care planning meeting may be an effective forum for resolving ongoing care problems; may be appropriate to refer family or resident to a private personal injury or medical malpractice attorney if serious injury or death results from the facility's negligence or failure to provide appropriate care.

C. Honoring Resident Preferences—Accommodation of Needs

1. A resident has the right under federal law to reside and receive services "with reasonable accommodation of individual needs and preferences except

where the health or safety of the individual or other residents would be endangered." 42 U.S.C. § 1396r(c)(1)(A)(v); 42 CFR § 483.15(e).

2. This includes the right to choose activities, schedules, and health care consistent with resident's interests, assessments and plan of care and to make choices about aspects of resident's life in the facility. 42 CFR § 483.15(b)(1) and (3).

3. If resident does not want to have his bath at 6 a.m. as scheduled for staffing reasons or wants to go to bed late and sleep late in the morning, as he's always done, the facility should make accommodations for those preferences. More problematic may be a resident who is a smoker and the facility is a smoke-free building—how does the facility accommodate this resident's needs without endangering the health or safety of other residents?

4. Approaches: involvement of ombudsman; oral request and/or letter requesting change and explaining why it's important to the resident and why the law requires the facility to honor the request (and possibly how it will help the facility in the long run); request change as part of care planning meeting; resident or family council to organize support for changes in procedures which would affect many residents.

5. "Culture change"—the movement to more resident-centered care.

D. Freedom from Restraints

1. A resident has the right to be free from physical or chemical restraints imposed for discipline or convenience and not required to treat the resident's medical symptoms. Restraints can only be imposed to ensure the physical safety of the resident or other residents and, except in an emergency, only with a written order of a physician which specifies the duration and circumstances under which the restraints are to be used. 42 U.S.C. § 1396r(c)(1)(A)(ii); 42 CFR § 483.13(a).

2. A physical restraint includes a vest or belt that ties the resident to the wheelchair or bed, or a bedrail; a chemical restraint is a behavior-modifying or psychoactive medication.

3. Often physical restraints can cause harm—e.g., asphyxiation from being tangled in the restraint; falls from becoming more unsteady due to less movement or from trying to crawl over a bedrail; depression or agitation from being tied to a chair.

4. If, for example, the facility wants to use a physical restraint to avoid wandering behavior, the resident or family can refuse and can ask the facility to explore other options such as walking with the resident, installing an electronic monitoring system, etc.

5. Chemical restraints should only be used when there is a diagnosed illness for which the medication is needed for the resident's treatment. Consider whether the medication is supposed to benefit the resident or the staff (to keep the resident quiet). Even if medication is prescribed by the doctor, the resident or his representative has the right to refuse the medication. 42 CFR § 483.10(b)(4); 42 CFR § 483.10(d)(3).

6. Issues regarding restraints and alternatives to the use of restraints should be discussed with the resident's doctor and can appropriately be raised in a care planning meeting.

E. Right to Privacy

1. Resident has a right to privacy with regard to accommodations, medical treatment, written and telephonic communications, visits, and meetings of family and of resident groups and to confidentiality of personal and clinical records. 42 U.S.C. § 1396r(c)(1)(A)(iii), (iv); 42 CFR § 483.10(e).

2. Does <u>not</u> give resident the right to a private room. 42 CFR § 483.10(e)(1).

3. Granny Cam question

F. Access and Visitation

1. The facility must provide <u>immediate</u> access to any resident by any representative of the Secretary, any representative of the State, the state long term care ombudsman or agency responsible for the protection and advocacy for the developmentally disabled or mentally ill, or the resident's physician. 42 U.S.C. § 1396r(c)(3); 42 CFR § 483.10(j). This apparently means access at any time without restriction.

2. The facility must also allow immediate access to the resident, subject to the resident's right to deny or withdraw consent at any time, by an immediate family or other relatives. 42 U.S.C. § 1396r(c)(3)(B); 42 CFR § 483.10(j)(1)(vii). This means that the facility cannot limit visiting hours for immediate family members or other relatives if the resident wants the person there.

3. The facility must permit immediate access, <u>subject to reasonable restrictions</u> and the resident's right to deny or withdraw consent at any time, to others who are visiting with the consent of the resident. 42 U.S.C. § 1396r(c)(3)(C); 42 CFR § 483.10(j)(1)(viii).

4. The facility must permit reasonable access to a resident by any entity or individual that provides health, social, legal or other services to the resident, subject to the resident's right to deny or withdraw consent at any time. 42 U.S.C. § 1396r(c)(3)(D); 42 CFR § 483.10(j)(2).

5. A married couple has the right to share a room with his or her spouse when they live in the same facility and both consent. 42 CFR § 483.10(m).

G. Grievances

1. A resident has the right to voice grievances regarding treatment or care that is (or is not) provided, without discrimination or reprisal and has the right to prompt efforts by the facility to resolve resident's grievances, including grievances about the behavior of other residents. 42 U.S.C. § 1396r(c)(1)(A)(vi); 42 CFR § 483.10(f).

2. A resident and resident's family also have the right to organize and to participate in resident or family councils, to meet in the facility, and to expect the facility to listen and act upon the grievances and recommendations of the residents and families concerning policies and operational decisions affecting resident care and life in the facility. 42 CFR § 483.15(c); 42 U.S.C. § 1396r(c)(1)(A)(vii).

III. Transfer/Discharge

A. Sources of the Law:

Federal: 42 U.S.C. § 1396r (c)(2)
42 C.F.R. § 483.12(a)

State: Va. Code § 32.1-138.1

Other: State Operations Manual – Appendix PP – Guidance to Surveyors for Long-Term Care Facilities

B. Definitions

1. Transfer – moving the resident from the facility to another legally responsible institutional setting. 42 CFR § 483.202. Bear in mind that transfer to a portion of the facility (a distinct part) from another portion with a separate certification under Medicare or Medicaid is considered transfer to another facility and entitles the resident to all the notice and appeal protections of any other transfer. 42 CFR § 483.12(a)(1); 42 CFR § 483.206(a);

2. Discharge – moving the resident to a non-institutional setting when the releasing facility ceases to be legally responsible for the resident's care. 42 CFR § 483.202;

3. Involuntary – whenever the transfer or discharge is initiated by the facility, not by the resident, whether or not the resident agrees to the facility's action. Transfer/discharge protections are applicable whenever the facility initiates the transfer/discharge.

C. Allowable Reasons for Involuntary Transfer or Discharge under Federal Law. 42 U.S.C. § 1396r(c)(2)(A); 42 CFR § 483.12(a)(2). The facility must permit a resident to remain in the facility and not transfer or discharge unless:

1. Transfer or discharge is necessary for the resident's welfare and the resident's needs cannot be met in the facility;

2. Resident's health has improved sufficiently so the resident no longer needs the facility's services;

3. The safety of individuals in the facility is endangered;

4. The health of individuals in the facility would otherwise be endangered;

5. The resident has failed, after reasonable and appropriate notice, to pay; or

6. The facility ceases to operate.

D. Documentation – for any of reasons 1-5, the resident's clinical record must be documented. 42 CFR § 483.12 (a)(3).

1. The resident's physician must document the clinical record for reasons 1 and 2;

2. A physician must make the appropriate documentation of the clinical record for reason 4;

3. Otherwise, the documentation may be done by any capable member of the facility's staff.

E. Notice

1. Must be in writing;

2. Must notify resident and, if known, a family member or legal representative of the transfer/discharge and the reasons in language and manner they understand;

3. Timing of the notice must generally be at least 30 days before the transfer;

4. Exceptions to the 30 day requirement – "as soon as practicable" – when

a. the safety of individuals is endangered;

b. the health of individuals is endangered;

c. the resident's health improves sufficiently to allow a more immediate transfer;

d. immediate transfer or discharge is required by resident's urgent medical needs;

e. the resident hasn't resided in the facility for 30 days.

5. Contents of the notice:

a. the reason for the transfer or discharge;

b. the effective date of the transfer or discharge;

c. the location to which the resident is to be transferred or discharged;

d. a statement of the resident's right to appeal the action to DMAS;

e. the name, address, and phone number of the State Long Term Care Ombudsman;

f. for residents with developmental disabilities, the mailing address and phone number of the agency responsible for the protection and advocacy of developmentally disabled;

g. for mentally ill residents, the mailing address and phone number of the agency responsible for the protection and advocacy of mentally ill.

F. Sufficient Preparation and Orientation to Ensure a Safe and Orderly Discharge/ Discharge Planning

1. Under 42 U.S.C. § 1396r(c)(2)(C) and 42 CFR § 483.12(a)(7), a facility is required to provide sufficient preparation and orientation to residents to ensure safe and orderly transfer or discharge from the facility.

2. The Guidelines to Surveyors at Tag F204 indicates that "sufficient preparation" means the facility should inform the resident of where he or she is going; take steps to assure safe transportation; actively involve the resident and family in selecting the new residence. Some examples of orientation might include trial visits to the new location; making sure possessions aren't left behind; orienting staff at the new facility of the resident's patterns; and other procedures to minimize anxiety over the move. Surveyors are encouraged to check social service notes to see if appropriate referrals have been made and if resident counseling has occurred.

3. These obligations are in addition to the facility's general obligation under 42 CFR § 483.20(l)(3) to have a post-discharge plan of care developed with the resident and family to "assist the resident to adjust to his or her new living environment."

G. State law requirements. Va. Code § 32.1-138.1.

1. Allowable reasons for discharge only

    a. if appropriate to meet that patient's documented medical needs;

    b. if appropriate to safeguard that patient or other patients from physical or emotional injury;

    c. nonpayment for his stay;

    d. with the informed voluntary consent of the patient or authorized decision-maker following reasonable advance notice.

2. Except in an emergency involving the patient's health or well being, requires prior consultation with the patient, patient's family or responsible party and patient's attending physician, or, if unavailable, the facility's medical director in conjunction with nursing director, social worker or another health professional.

3. For an involuntary transfer or discharge, the attending physician or the medical director of the facility must make a written notation in the patient's record approving the discharge or transfer "after consideration of the effects of the transfer or discharge, appropriate actions to minimize the effects of the transfer or discharge, and the care and kind of service the patient needs upon transfer or discharge."

4. Reasonable advance written notice must be given to the patient. "Reasonable under the circumstances" or at least 5 days prior to discharge or transfer.

H. Right to Refuse Certain Transfers. 42 CFR § 483.10(o)

1. A resident has the right to refuse a transfer to another room within the institution if the purpose is to relocate a resident of a SNF from a distinct part of the facility that is a SNF to a non-SNF part or a resident of a NF from the distinct part that is NF to a distinct part that is SNF, for purposes of obtaining Medicare or Medicaid eligibility. The Surveyors Guidelines, Tag F177, however, suggests that refusal to transfer from one portion to the other may forego the possibility of Medicare or Medicaid coverage if the resident is not in a certified bed, so this is probably only helpful to a resident if the beds are dually certified.

I. Likely Scenarios

1. Non-payment—(1) possible Medicaid eligibility issue and may need 2 appeals—of the eligibility decision and of the discharge; or (2) could be failure to pay patient pay obligation or private pay monthly bill;

2. Facility says Resident is Endangering the Safety of Others;

3. Facility says transfer or discharge is necessary for the resident's welfare and the resident's needs cannot be met in the facility;

4. Facility says Resident no longer requires nursing home care.

J. Possible Defenses

1. Defective Notice—e.g. doesn't give location to which to be transferred; fails to give date of transfer or has not given required amount of notice; fails to state appeal rights; fails to give name, address and phone number of State Long Term Care Ombudsman;

2. Failure to Document the Record;

3. Failure to Provide Sufficient Discharge Planning—e.g. sending resident to a home where no one can care for him without personal care services in place; sending resident to a facility far away from all family and friends; sending resident to another facility no better equipped to provide for his care;

4. Stated Grounds for Transfer/Discharge Does Not Exist—e.g. Behavior Does not Rise to Level of Endangering the Safety of Others; or notice is premature because there is no balance owed at time of notice--just a fear that there will be a balance after Medicaid cut off.

K. Options for Challenging a Transfer/Discharge

1. Negotiating with Facility

2. Involvement of Ombudsman

3. Medicaid Appeal—fair hearing

4. Appeal of an Unfavorable Hearing Decision to Circuit Court under the Administrative Process Act

5. Federal Court for injunctive relief

IV. Right to be Readmitted from the Hospital or Therapeutic Leave/ Bed Hold and Readmission

A. Before a nursing home transfers a resident to a hospital or allows a resident to go on therapeutic leave, the facility must provide written information to the resident and a family member or legal representative specifying the duration of the bed-hold policy under Medicaid state plan and the facility's policy regarding bed-hold periods and a written notice specifying the duration of the bed hold policy must be provided the resident and family member at the time of transfer to a hospital or for therapeutic leave. Note: 2 notices seem to be required. 42 U.S.C. §1396r(c)(2)(D); 42 CFR § 483.12(b).

B. A facility must have a written policy under which a resident whose hospital stay or therapeutic leave exceeds the state's bed-hold period, must be readmitted to the facility immediately upon the first availability of a bed in a semi-private room as long as the resident still requires nursing home care and is eligible for Medicaid. 42 U.S.C. §1396r(c)(2)(D)(iii); 42 CFR § 483.12(b)(3).

C. The Guidelines to Surveyors, Tag F206, clarifies that the facility must readmit the resident to the first available bed even if the resident has an outstanding Medicaid balance, but the resident could then be transferred due to nonpayment (but only after documentation and notice requirements are followed).

D. Facilities often ignore this regulation and attempt to get rid of nonpaying or difficult" residents by sending them to the hospital and then refusing to take them back.