

**PROTECTING ESSENTIAL HUMAN CAPABILITIES
OF ELDERS IN INSTITUTIONAL CARE**

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Introduction:

The world has moved past the traditional definition of health, while institutional care in America has not. The World Health Organization (WHO) defines health as a state of complete well-being, and not just the absence of disease¹. However, this ideal does not extend to millions of seniors in long-term care facilities across the nation.

Consider Frank², a retired veteran in his seventies who is a resident at The Manor, a low-income assisted living home. Frank suffers from a mild case of dementia, which causes him to sometimes forget to take his medication. The Veterans Administration (VA) has determined that he is ineligible for in-home care, even though he has a wife at home whom he hasn't seen for several months. His Veteran Benefits, combined with his particular situation make him ineligible for additional Medicare/Medicaid assistance, leaving him with no other options.

Like countless other low-income assisted living facilities across the nation, The Manor offers little more to its residents than a convenient place to die in. There are no activities and programs offered for residents to pursue their personal interests. Frank and the other residents sit in a small common room devoid of conversation for hours at a time, staring with indifference at a dilapidated TV that has been set to the same channel for months. The specific needs of each resident are left unaddressed, even needs as simple as blankets for the winter, paper and stamps to write letters with, or even a small bottle of cream to treat irritated skin. The institution is understaffed: four or five nurses must handle the needs of around 60 residents. The few nurses present are stressed and unequipped to deal with the sensitive needs of residents. The wants and anxieties of residents are misinterpreted as misbehavior, and compliance is earned through bribing residents with cigarettes. I have

¹ "Mental Health Strengthening Our Response," World Health Organization, September 2010.

² <http://www.who.int/mediacentre/factsheets/fs220/en/>

² Not actual name

seen incontinent residents left wet or soiled for 30 minutes at a time. The institution is isolated from the outside world: few visitors are ever seen besides the volunteers, and few residents are ever allowed to leave.

Despite being denied the basic capabilities essential to be human, Frank has not lost all of his optimism and liveliness. He greets us with warmth, expresses genuine interest in our lives, and participates in simple activities such as BINGO with enthusiasm. He adores children, and looks forward to the few moments he can spend with his wife. In another place with real opportunities, I have no doubt that he would have found contentment and enriched the lives of others. Instead, the combined failures of policies and those responsible for his care have consigned him to this poor imitation of human life.

Health and human capabilities:

The state of health is a complicated concept, with multiple proposed definitions. The crudest of these is the traditional definition, which frames health as the mere absence of disease. The WHO extended this definition to include social and emotional components. Other organizations further expand this definition to include different dimensions of human potential. The National Wellness institute recognizes eight dimensions of health, which include spiritual, intellectual, occupational, and cultural wellness³. The Alliance Institute states that health also encompasses human qualities such as love, intuition, the power to create and adapt, and think unhindered⁴. Norman Daniels indicates that health can also be defined from the perspective of its impact on opportunities⁵. We can reconcile these various definitions of health if we define health through capabilities, and then relate these capabilities to a broad definition of human rights.

³ Definitions of Health. Pacific Northwest Foundation
http://www.pnf.org/Definitions_of_Health_C.pdf

⁴ Ibid.

⁵ Daniels, Norman. Just Health. New York: Cambridge University Press, 2008

The concept of a normal range of opportunities can be linked to the capabilities approach that Sen has developed⁶. These capabilities are defined through two fundamental principles. First, capabilities are the freedom to choose from a set of different functionings a self-determined path towards goals and values. Second, capabilities represent the freedom to participate as a full citizen, in the social, political, and economic life of the public⁷. These two principles of capabilities will be the framework for how we discuss the state of institutional care in America.

This discussion focuses on the less tangible measurements of capabilities that institutions and policies have neglected. National policies are often focused on improving healthcare statistics alone, while seniors themselves want something different: meaningful and dignified human lives. Institutional care has a greater obligation than meeting basic health needs. Its purpose should also be to create enabling environments that allows seniors to live fulfilling, dignified, and creative lives. A full range of capabilities includes social acceptance, a sense of purpose and participation, access to social and emotional support, and a range of opportunities available for personal growth and enrichment⁸. These are each basic liberties that are essential components of normal social functioning, and of total health as we have defined it.

I pose this fundamental question throughout the discussion: Does institutional care protect the health of seniors, as we have defined it in terms of capabilities? I contend that it does not in its current state. Residents are disempowered through widespread abuse and neglect. Their independence and individual needs are considered dispensable.

⁶ Sen, Amartya. 1993. *Capability and Well-Being*. Oxford University Press:

⁷ Sen, Amartya. 1992. *Inequality Reexamined*. Cambridge, MA: Harvard University Press.

⁸ Nussbaum, Martha C. 2003. "Capabilities as Fundamental Entitlements: Sen and Social Justice." *Feminist Economics*. pp.42-43

Ethical arguments for protecting resident capabilities:

To support a moral imperative for health, we must define the ethical framework which allows us to assert that access to social participation is a principle of justice. We can approach this claim through two influential philosophers and ethicists of our time.

John Rawls argues in *A Theory of Justice* (1971) that societies have a moral obligation to promote a fair range of opportunities for all citizens⁹. Implicit in this assumption is the idea that we have an ethical mandate to guarantee a basic level of opportunities for all people, regardless of socioeconomic status, age, circumstance, or personal characteristics. It is a dangerous misconception to assume that opportunities are things that are reserved for younger generations, since this leads us to marginalize the needs of seniors. The American ethos declares that *all people* have an inalienable right to opportunity and dignity. Our senior citizens, who have contributed a lifetime of service, raised our generation, and fought to secure our freedoms, are no exception to this ideal.

Martha Nussbaum frames the principle of a normal range of opportunities in the terms of ten core capabilities. These capabilities are listed as follows¹⁰:

Life	Practical Reason
Bodily Health	Affiliation
Bodily Integrity	Other species
Sense, Imagination, and Thought	Play
Emotions	Control over one's environment

Note that of these core capabilities that Nussbaum defines, two of them are based on the traditional definition of health that national rhetoric remains fixated on. Nussbaum identifies each of these capabilities as central requirements of a dignified life, and a core component of what it means to be human. All reasonable societies must protect a minimum

⁹ Rawls, John. 1971. *A Theory of Justice*. Belknap Press of Harvard U.

¹⁰ Nussbaum, Martha C. 2011 *Creating Capabilities: The Human Development Approach*. Belknap Press of Harvard University Press, 2011. pp. 7-8

threshold of each of these capabilities, as a basic principle of societal justice¹¹. Furthermore, if we neglect one of these capabilities to promote the other, we have fallen short of justice. In a practical context, this means that institutions cannot continue to undermine capabilities such as social interaction and personal respect (classified under affiliation) in the name of clinical health. Nussbaum also stipulates that whenever institutions fail to meet the minimum threshold, immediate assistance becomes a moral imperative¹².

Defining a normal range of opportunities:

When we strive to protect a normal range of opportunities, we must be aware that this range often varies between different age groups. A normal range of opportunities is based on what is important for different individuals at different stages of life. Daniels defines these differences as the set of life plans reasonable persons are inclined to construct for themselves¹³. The capabilities approach focuses on freedom and self-determination, leading us to promote a set of opportunities that accommodates what is important to each individual. Residents of institutional care facilities are often deprived of a fundamental level of control over their lives, unable to pursue the personal interests and relationships that are essential to a meaningful life. When we consider what opportunities we wish to protect, we must center our approach around one salient question: How can we provide our elders with meaningful freedom to fashion their own lives?

Daniels indicates that a senior in a retirement home has far different needs and aspirations from a college graduate¹⁴. The college graduate might be concerned with pursuing a successful career, finding a spouse, and raising children in a nurturing environment. A nursing home resident has a different set of concerns, which are of equal relevance in the context of social justice. After a lifetime of contribution and service in the

¹¹ Ibid.

¹² Ibid.

¹³ Daniels, pp.35

¹⁴ Daniels, pp.175

workforce, most retirees value a nurturing environment to pursue personal interests and participate in enriching social interaction. Most people consider opportunities as something reserved for adults and children, in the context of equal access to jobs and education. This is a dangerous misconception, since it causes us to marginalize the opportunities of seniors. Although we must be conscious of distributive justice and the opportunities of other populations, there is no possible ethical justification for the slow death of isolation and neglect that some seniors confront in institutional care. Just as we are committed to promoting equitable education and jobs for children and adults as a matter of full social participation, we must also ensure that seniors are protected from disempowerment and provided with self-determination. This means that must be committed to providing access to social interaction, enrichment, and as much personal freedom as is practicable.

We must also be conscious of differences in ranges of opportunities on an individual level. Martha Nussbaum defines capabilities as “what each person is able to do and to be¹⁵.” Each person has a different level of potential, based on his or her personal strengths and talents. Each person also has a different set of personal values, which our policies should strive to accommodate. Some seniors attach enormous social and emotional value to their places of worship. Others wish to pursue artistic and musical interests. Daniels indicates that a number of elders would be amenable to flexible work opportunities¹⁶. According to Nussbaum, these capabilities should be as relevant in policies as health itself. Although in practical terms priorities might have to be set, these individual freedoms are all of central relevance to social justice¹⁷. Institutions should make a practicable effort to provide personal freedom. In practical terms, this effort starts with asking residents a simple, sincere question: “What would YOU like to do?” This is a question I have never heard asked at the Manor.

¹⁵ Nussbaum, pp. 6

¹⁶ Daniels, pp.184

¹⁷ Nussbaum, pp.8

An overview of institutional care in America:

There are two predominant modes of care for dependent seniors: home care and institutional care. This discussion focuses on issues and recommendations for institutional care, with a brief assertion that, when feasible, in-home care tends to be preferable to institutional care in terms of both cost and contentment. The cost of a home health aide in 2013 is \$19 an hour or \$2,470 per month. In comparison, the average cost of a private nursing home is \$7,840 per month, and the average cost across assisted living facilities is \$3,427 per month¹⁸. Home care is also more comfortable than institutional care, since seniors can remain in their local communities and do not have to confront the personal restrictions associated with institutional care. AARP studies indicated that 81% of individuals over age 50 preferred to remain in their homes¹⁹. Furthermore, the rate of depression is around three times lower (11-14%) for in-home care, when compared to nursing home residents (29-52%)²⁰. It is advisable that whenever healthcare needs are low enough to permit effective in-home care, our policies should provide seniors with the full freedom to select either option.

Some seniors require (or prefer) more assistance than home care can provide, and turn towards institutional care instead. In other cases, state funding policies do not support certain home-based services. There is a strong institutional bias in federal support for long-term care. As of 2010, 21 states do not participate in Medicaid's Personal Care Services (PCS) programs²¹. Furthermore, home health services tend to be insufficient for all but the most capable seniors: Virginia Medicaid, for example, covers a maximum of 32 health aide

¹⁸ Understanding What Home Care Really Costs.

<http://www.homeinstead.com/services/Pages/whathomecarereallycosts.aspx>

¹⁹ Cannuscio C, Block J, and Kachawi I. Social Capital and Successful

Aging: The Role of Senior Housing, *Annals of Internal Medicine*, September 2, 2003, pg. 397

²⁰ Mental Health and Older Adults: Depressive Disorders. pp.2

<http://www.cswe.org/File.aspx?id=23509>

²¹ State Health Facts: Medicaid Benefits. <http://kff.org/medicaid/state-indicator/home-health-services-includes-nursing-services-home-health-aides-and-medical-suppliesequipment/>

visits per year²². Institutional care facilities themselves can be classified as either assisted-living facilities or nursing homes. In general, nursing homes provide more extensive medical services, such as 24 hour skilled nursing care and medical supervision. Assisted living facilities tend to offer more personal freedom than nursing homes, since residents are under less medical supervision and are under fewer restrictions. These are broad classifications, and the environment and care model of some assisted living facilities bears a close resemblance to nursing homes.

The effectiveness of institutional care is an issue that will become more and more prominent with each passing decade, as the population of seniors expands. In 2030, the population of individuals over 65 is expected to double to 72 million. Meanwhile, studies indicate that over 40% of people over age 65 will enter institutional care at some point. As of now, 3.2 million seniors live in nursing homes while around 900,000 live in assisted-living facilities²³. While assisted living facilities tend to be funded through private means, over 70% of nursing home expenses are funded through federal programs such as Medicaid²⁴. As of 2011, 69% of nursing homes are for-profit enterprises, which tend to produce poorer resident outcomes than non-profit facilities²⁵.

Improving Institutional Care: 1965 to Present

Institutional care in America has had a troubled past, and faces an uncertain future. Nursing homes rose to prominence after 1965, following the establishment of Medicare. These institutions often provided substandard care, as a consequence of ineffective federal regulation and enforcement. Critics labeled these houses as “warehouses for the old” or “halfway houses between society and the cemetery”, and people feared ending their lives in

²² Ibid.

²³ Long Care Services in the United States: 2013 Overview.
http://www.cdc.gov/nchs/data/nsitcp/long_term_care_services_2013.pdf

²⁴ Ibid.

²⁵ Vikram R. Comondore et.al. 2009. "Quality of care in for-profit and not-for-profit nursing homes: systematic review and meta-analysis," British Medical Journal

these inhospitable facilities²⁶. As nursing homes expanded so did their numerous issues, which became more and more salient to the public. Numerous studies throughout these following decades reported that residents of nursing homes were being abused, neglected, and given inadequate care.

In 1986, the National Citizens' Coalition for Nursing Home Reform, an advocate group concerned about the substandard care in nursing homes, released a set of reform guidelines emphasizing the importance of residents' rights and assessments. With widespread support from the AARP and the CMS, the coalition conducted focus groups to learn how nursing home residents themselves defined exceptional nursing care. The central message gleaned from these focus groups was that *quality of care* and *quality of life* are inseparable and of equal importance to residents. This fundamental principle contributed to a sweeping set of nursing home reforms known as the Nursing Home Reform Act, which was incorporated into the Omnibus Budget Reconciliation Act (OBRA) of 1987²⁷. The passage of OBRA was a remarkable example of how all interested parties- consumer advocates, industries, and researchers- could cooperate in a government-sponsored commission to transform national policies²⁸.

The OBRA constitutes a national promise to prioritize and protect the personal well-being of residents. It mandated that "residents [are] to be provided with services sufficient to attain and maintain his or her highest practicable physical, mental, and psychosocial well-being", and was the first explicit law in the healthcare sector that recognized the social and emotional components of health²⁹. The OBRA also established a bill of rights for residents, which contained provisions for social needs, self-determination, abuse prevention, and the

²⁶ The History of Nursing Homes. <http://www.4fate.org/history.html>

²⁷ Koren, Mary J. Person-Centered Care for Nursing Home Residents: The Culture-Change Movement. *Health Affairs*, 29.2 (2010). pp.312-313.

²⁸ Nursing Home Care Quality: 20 Years After the Omnibus Budget Reconciliation Act of 1987. <http://kaiserfamilyfoundation.files.wordpress.com/2013/01/7717.pdf>

²⁹ Ibid.

protection of basic dignities³⁰. The law enabled residents to voice grievances without fear of retaliation or discrimination. It also protected residents from the careless and inhumane use of restraints, which was a common form of discipline at the time³¹.

OBRA offered three important improvements to the federal regulation of nursing homes. First, OBRA established new, higher standards that were much more resident focused than previous standards. Along with the basic rights mentioned before, the law also upgraded staffing requirements for nursing homes and raised certification requirements to a minimum of 75 hours of training³². Second, OBRA established a set of enforcement guidelines for nursing homes in violation of institutional standards that incorporates a range of sanctions for noncompliant homes. States were now required to conduct periodic inspections, which included resident interviews and direct observation of care³³. Third, OBRA merged Medicare and Medicaid certification for nursing homes into a single process, with new standards that were much higher than had existed for facilities before³⁴. To streamline care and make institutions more accountable, OBRA required all nursing homes to utilize and report personalized data as a uniform set of information called the Minimum Data Set (MDS). The MDS provides both facilities and federal agencies with detailed and standardized information about the status of residents that can be used for care planning, assessing the impacts of policies, and revealing deficiencies in care³⁵.

Since the passage of OBRA, noticeable progress has been made in improving the outcomes of nursing home residents. MDS data shows there has been a significant reduction in the use of mechanical or chemical restraints. These are devices or chemicals that restrict

³⁰Federal Nursing Home Reform Act: OBRA 1987 Summarized.
<http://www.ncmust.com/doclib/OBRA87summary.pdf>

³¹ Ibid.

³² Wiener et.al. Nursing Home Care Quality: 20 Years After the Omnibus Budget Reconciliation Act of 1987. *The Kaiser Family Foundation*. (2007)
<http://kaiserfamilyfoundation.files.wordpress.com/2013/01/7717.pdf>

³³ Ibid

³⁴ Ibid

³⁵ Ibid

freedom of movement, or inhibit control over motor functions. The use of such methods represents a direct assault on personal freedom, a denial of basic human dignities, and is associated with decreased muscle tone, pressure sores, incontinence, and depression³⁶. In 1980, the misuse of restraints as a tool of discipline or convenience was estimated to be as high as 41% across facilities³⁷. The use of restraints has since then declined to 10.3% in 2007, due to OBRA provisions that place strict limitations on their use³⁸. MDS statistics have also reported moderate increases in staffing levels since the implementation of OBRA, with around a 25% increase from 1985 to 1995. This is coupled with the improvement that aides are required to have a modest amount of training before caring for residents³⁹. Assisted-living facilities also became prominent during this period, developed in 1981 as an alternative model of institutional care that provides basic medical attention while emphasizing greater independence.

Limitations of federal policies: OBRA (1987) and ACA (2010)

While we have come a long way from the “warehouses of the old” that described nursing homes in the 1970s, the picture of institutional care in America is still quite bleak. While some facilities provide an exceptional level of care and abundant opportunities, far more institutions provide little more than a bed and a place to die. The few improvements we have made have highlighted the significant challenges that remain. More than 90% of all certified facilities were cited for one or more deficiencies in 2006. Staffing levels and qualification remains inadequate across the nation⁴⁰. Alarming rates of abuse, neglect, social isolation, and depression still define the face of institutional care in America. Studies in 2003

³⁶ Institute of Medicine (2001). *Improving the Quality of Long-Term Care*. Washington, DC: National Academy Press.

³⁷ Strumpf, N.E., and Tomes, N. (1993). Restraining the troublesome patient: A historical perspective on a contemporary debate. *Nursing History Review*, 1: 3–24.

³⁸Wiener et.al pp. 15

³⁹Wiener et.al. pp.3

⁴⁰Ibid

found that 30% of older people would rather die than move to a nursing home, with another 26% expressing extreme hesitation⁴¹.

While assisted living facilities can offer an attractive alternative to nursing homes for more capable residents, there is almost no federal regulation of these facilities except through Medicaid fee waivers. The task of regulating assisted living facilities falls on the States: as a result, state standards and regulation practices are varied and incomparable. Several studies have raised concern about the staffing patterns and resident outcomes of assisted living facilities. Studies of assisted living across four states reported insufficient and undertrained staff, as well as significant rates of medication errors. Separate studies in 1998 found some positive aspects of assisted living, but also revealed some basic needs of residents such as toilet assistance (26%), locomotion (12%), and dressing (12%) were unmet. Lower-income facilities often lack the amenities, services, and opportunities of more comprehensive service settings⁴². Assisted living facilities are as varied as the state policies that regulate them, and cater to a broad spectrum of socioeconomic class. Some facilities provide effective medical supervision, while also offering a remarkable degree of independence, recreation, and social participation. Other facilities cannot provide their residents with basic human dignities, a single ounce of enrichment, or even extra blankets during a cold winter. Nowhere is social injustice more visible than the differences in the lives of residents between privileged and underfunded assisted living facilities.

National policies are as effective as the tools provided to them, and OBRA is no exception. A serious disconnect exists between the high standards OBRA provisions support, and the inadequate enforcement of these regulations. Serious complaints often remain uninvestigated for months, and severe care deficiencies remain unaddressed with relevant

⁴¹ Mattimore T.J., et al. (1997). Surrogate and physician understanding of patients' preferences for living permanently in a nursing home. *Journal of the American Geriatrics Society*, 45: 818-824.

⁴² Hawes, C., Phillips, C.D, and Rose, M. (2000). *A National Study of Assisted Living for the Frail Elderly: Results of a National Survey of Facilities*. U.S. Department of Health and Human Services. <http://aspe.hhs.gov/daltcp/reports/facres.htm>

sanctions⁴³⁴⁴. Large numbers of marginal nursing homes cycle in and out of compliance, temporarily correcting their issues when evaluated, then lapsing into noncompliance until the next inspection⁴⁵. Even the reliability of the MDS data itself is questionable, since facilities fill out the MDS forms unsupervised, and the details of each assessment are almost never audited⁴⁶. These failures in implementation and enforcement have blunted the impact of the OBRA provisions. Since around 1999, improvements in nursing homes have appeared to reach a plateau, or have even deteriorated⁴⁷. However, the recent passage of the Affordable Care Act (ACA) in 2010 promises new progress in these areas.

The 2010 ACA is the first piece of legislation since OBRA to expand legislation protecting the well-being of nursing home residents⁴⁸. The provisions are aimed at improving the effectiveness of data reporting, and protecting residents from mistreatment. Most of the major provisions can be summarized as:

- (1) Nursing homes must publish detailed information about administration and staff, such as nursing hours, staff ratios, ownership structure, turnover, and staff retention. Facilities will also be required to report detailed information related to resident care (such as health reports, inspection results, penalties, and complaints) to the CMS Nursing Home Compare website⁴⁹.

⁴³ U.S. Government Accountability Office (2005). *Despite Increased Oversight, Challenges Remain in Ensuring High-Quality Care and Resident Safety* (GAO-06-117). Washington, DC: U.S. Government Accountability Office

⁴⁴ U.S. Government Accountability Office (2007a). *Nursing Homes: Efforts to Strengthen Federal Enforcement Have Not Deterred Some Homes from Repeatedly Harming Residents*. GAO-07-241. Washington, DC: U.S. Government Accountability Office.

⁴⁵ Ibid.

⁴⁶ Harrington, C., Carrillo, H., Wellin, V., and Burdin, A. (2003a). *Nursing Facilities, Staffing, Residents, and Facility Deficiencies, 1996 Through 2002*. San Francisco: Department of Social and Behavioral Sciences, University of California.

⁴⁷ Wiener et.al. pp.3

⁴⁸ Implementation of Affordable Care Act Provisions to increase Nursing Home Transparency, Care Quality, and Abuse Prevention. *The Henry J. Kaiser Family Foundation*. (2011) <http://www.kff.org/medicare/upload/8406.pdf>

⁴⁹ Ibid.

(2) New nurse aides must undertake an additional 6 hour training course in dementia and abuse prevention that focuses on the misuse of chemical sedatives used to restrain residents. Standardized background checks must also be conducted on all new nurse aides⁵⁰.

Due to the recent nature of the ACA, these provisions are still in development or still await implementation. The enforcement mechanisms for these regulations are incomplete, and most of the data on Nursing Home Compare remains unaudited⁵¹. Critics have also accused these provisions of being too reserved, with no measures to increase penalties for noncompliant nursing homes or regulations addressing the pervasive understaffing of facilities⁵². More time and resources for implementation and enforcement are needed for these ACA provisions to have a substantial impact on the issues that confront institutional care.

The causes of abuse and neglect:

The abuse or neglect of dependent seniors is one of the greatest forms of complete disempowerment, and must be addressed before we can hope to empower residents with real capabilities. We can frame this issue through Isaiah Berlin's concept of negative freedom, which can be summed up as freedom from all forms of coercion or exploitation⁵³. This includes the freedom from abuse and assault, as well as from the imposed helplessness of caretaker neglect. Sen indicates that negative freedom, in some cases, is a precondition for the substantial freedom we hope to provide⁵⁴. The current situation of institutional care in America is grim. In 2000, a sample of 2000 nursing home residents 44% reported that

⁵⁰ Ibid.

⁵¹ Ibid.

⁵² Ibid.

⁵³ Berlin, I. "Two Concepts of Liberty." In Isaiah Berlin Four Essays on Liberty. Oxford: Oxford University Press. (1958)

⁵⁴ Vizard P. The Contributions of Professor Amartya Sen in the Field of Human Rights. The London School of Economics 2010
http://eprints.lse.ac.uk/6273/1/The_Contributions_of_Professor_Amartya_Sen_in_the_Field_of_Human_Rights.pdf

they had been abused or neglected, while another 95% had seen a resident suffer the same⁵⁵. This troubling statistic is also observable when the same question is posed to nursing assistants themselves: 2010 studies indicated that over 50% of nursing assistants admitted to mistreating residents, with two-thirds of those cases involving neglect⁵⁶. Thirty percent (5,283 facilities) of nursing homes have been cited for over 9,000 instances of abuse from 1999 to 2001⁵⁷. These numbers provide a shameful representation of the disempowerment and injustice that seniors face in these facilities. Before we can confront the widespread abuse and neglect of residents, we must understand how these issues arise and remain unaddressed. Both institutions and federal/state policies are to blame for these gross inadequacies.

The first problem is that institutions are not held accountable for abuse, and are not penalized enough to make them reform. All reports from this decade to the General Accounting Office repeat the same message: nursing home residents need both stronger and more immediate protections. These studies also indicate that there are serious flaws within the processes that states use to detect, investigate, resolve, and prevent mistreatment in facilities⁵⁸. For each case of abuse that goes reported, it is estimated that 5 more incidences of abuse go unnoticed. Families, concerned staff, and residents are often reluctant or unwilling to file official complaints. Residents and families often fear that a formal complaint might cause retaliation against the resident. Across long-term care facilities in Atlanta, 44% of the residents had seen abuse and had not reported it. Half of those cases were because the resident in question feared retaliation. In other cases, no report is filed because people believe that the entire process is futile. In the same studies

⁵⁵ Abuse of Residents of Long Term Care Facilities, National Council on Elder Abuse, February 2012, pg. 1-2, "http://www.centeronelderabuse.org/docs/Abuse_of_Residents_of_Long_Term_Care_Facilities.pdf"

⁵⁶ Ibid.

⁵⁷ Gibbs, Lisa and Mosqueda Laura. Confronting Elder Mistreatment in Long-Term Care. National Council on Elder Abuse. (2004)

⁵⁸ Ibid.

mentioned, 38% of residents claimed that reporting wouldn't do any good⁵⁹. Health care professionals and nurses also often fail to report incidences of abuse or severe neglect, despite their legal obligation. Eighty-three percent of critical care nurses in Florida reported seeing evidence of abuse in older persons admitted for treatment, but just 36% of them filed an official report⁶⁰. As mentioned, even when cases of abuse or neglect are reported, these complaints often remain uninvestigated and unaddressed for weeks or months. This is a cruel time span for victims of abuse or neglect to face.

Even when violations are detected, state and federal enforcement measures are often inadequate. As of now, the ultimate sanction is to revoke Medicaid and Medicare certification from facilities, although OBRA expanded the range of sanctions to include civil money penalties, the ability to require staff training, and denial of payment for new admissions⁶¹. However, evidence shows that these sanctions are either too small or too infrequent to be an effective deterrent, or are applied too long after a violation have occurred⁶². GAO-commissioned studies of long-term care facilities with serious violations in four states found that half these facilities were out of compliance on follow-up inspections⁶³. Nursing homes often continue to rotate in and out of compliance, due to the ineffectiveness of short-term sanctioning policies. The Manor is an example of such an institution, receiving multiple violations, but obscuring them in time to avoid state penalties⁶⁴. The numbers of facilities that even receive sanctions is low: few nursing homes are ever decertified⁶⁵, civil

⁵⁹ Atlanta Long-Term Care Ombudsman Program. *The Silenced Voice Speaks Out: A Study of Abuse and Neglect of Nursing Home Residents*. Atlanta Legal Aid Society; Washington, DC: National Citizens Coalition for Nursing Home Reform; 2000.

⁶⁰ Pettee EJ. Elder abuse: Implications for staff development. *Journal of Nursing Staff Development*. 1997;13(1):7-12.

⁶¹ Wiener et.al, pp.28

⁶² U.S. Government Accountability Office (2007a). *Nursing Homes: Efforts to Strengthen Federal Enforcement Have Not Deterred Some Homes from Repeatedly Harming Residents*. GAO-07-241. Washington, DC: U.S. Government Accountability Office.

⁶³ Ibid.

⁶⁴ The Manor of Natural Bridge Inspection Results: Virginia Department of Social Services. <http://www.dss.virginia.gov/facility/search/alf.cgi?rm=Details;ID=8202>;

⁶⁵ U.S. Government Accountability Office (2007a).

penalties are issued for just 2% of all violations⁶⁶, and it takes an estimated 14 months for penalties to be applied from the time of violation⁶⁷. The need for more aggressive, immediate enforcement of federal and state regulations is clear, if these policies and promises represent more than just words.

The second major cause of abuse and neglect is that the standard of care in most facilities is far below an acceptable standard. The vulnerable state of residents puts them at great risk for mistreatment from their caregivers. Residents with severe disabilities such as dementia are at an even higher risk for abuse and neglect. Studies in 2010 found that 47% of long-term care residents with dementia had suffered abuse from their caregivers⁶⁸. While these actions are not condonable, the underfunded and understaffed condition of some facilities contributes to their occurrence. When asked about the abuse of residents, a CNA from South Carolina responded:

Yeah, I've seen it. Things like rough handling, pinching, pulling too hard on a resident to make them do what you want. Slapping, that too. People get so tired, working mandatory overtime, short-staffed. It's not an excuse, but it makes it so hard for them to respond right.⁶⁹

In times of short-staffing, it is almost impossible for residents to avoid some degree of neglect. Stressful conditions and long hours also leave nurses irritable and exhausted, and more prone to mistreat residents. The staff-to-patient ratio is the single best predictor of neglect, and also has a powerful correlation with rates of abuse⁷⁰. In 2001, the CMS conducted research to determine staffing thresholds below which adequate care was

⁶⁶ Tsoukalas, T., Rudder, C., Mollot, R.J., Shineman, M., Lee, H.Y., and Harrington, C. (2006). The collection and use of funds from civil money penalties and fines from nursing homes. *The Gerontologist*, 46(6): 759–771.

⁶⁷ U.S. Department of Health and Human Services, Office of the Inspector General (2005). *Nursing Home Enforcement: The Use of Civil Money Penalties*. Washington, DC: Office of the Inspector General, U.S. Department of Health and Human Services.

⁶⁸ Wiglesworth A, Mosqueda L, Mulnard R, Liao S, Gibbs L, & Fitzgerald W. (2010). Screening for abuse and neglect of people with dementia. *Journal of the American Geriatrics Society*.58(3), 493-500.

⁶⁹ Hawes C, Rose M, Phillips C. *A National Study of Assisted Living: Results of a National Survey of Facilities*. Washington, DC: U.S. Department of Health and Human Services. 1999

⁷⁰ Natan, Merav B. and Lowenstein, Ariela. Study of Factors that affect abuse in older people in nursing homes. *Nursing Management* 17(8). December 2010

compromised: the report recommended a *minimum* staffing ratio of 4.1 hours of care per resident day, which was 10% higher than *average* staffing levels then⁷¹. Inadequate staff training and high staff turnover are also huge contributing factors to the prevalence of abuse and neglect. High staff turnover is the single best predictor of abuse in facilities⁷², which is problematic when we consider that the average turnover rate for nurse-aides is 65% in the United States⁷³. Either problem limits staff from developing knowledge of the patients and their needs and preferences. High turnover prevents patients from developing rapport with staff, leaving patients insecure and more prone to belligerence. Abuse can happen as a result of misunderstanding, rather than malicious intent⁷⁴. Although it is reported that around 60% of residents at nursing homes have some degree of dementia, in 37 states nursing assistants are not required to receive training in dementia care or abuse prevention⁷⁵. It is no wonder then that most CNAs are unable to understand the personal needs and anxieties of their patients, and are unable to deal with sensitive situations that require individualized treatment plans.

Recommendations for confronting abuse and neglect:

Reforms are needed to hold institutions accountable for their actions, and to ensure that the formal complaint process is both safe and effective. First: while the information that facilities are required to report to Nursing Home Compare (as per ACA 2010) is detailed, it is also unreliable because most of it is self-reported and unaudited. Better review processes are needed for the CMS and the public to evaluate and correct deficiencies. Second: while the 2010 ACA implemented a standardized complaint form for residents and their representatives, there is to date no federal provisions for formal complaint procedures and

⁷¹ Howe, Carol. Staffing Ratios in Nursing Homes. Arizona Geriatrics Society 15.(2), August 2009.

⁷² Natan and Ariela, pp. 23

⁷³ Mosqueda and Lauren, pp.3

⁷⁴ Natan and Ariela, pp. 24

⁷⁵ Wiglesworth et.al pp.495

the protection of those involved⁷⁶. Measures to protect and streamline the complaint process must be prioritized, to improve the detection of abuse in institutions. These complaints must be investigated sooner, and the entire process must be more accessible so complainants feel that their efforts are justified. Third: more aggressive enforcement of existing regulations must be implemented. Federal and state sanctions should be prompter, more stringent, and issued more often to serve as an effective deterrent to noncompliance. Enforcement agencies should ensure that facilities with persistent violations and chronic poor-performance are either reformed or put out of business. All these provisions must all be applicable for assisted-living facilities in addition, to avoid marginalizing the needs of 900,000 seniors living in such arrangements.

Reforms are also needed to increase the standard of care at institutions. This will not occur without significant financial investments, but this price must be paid if we hope to ever protect residents from the injustices of abuse or neglect. First: federal law must establish a minimum staff-to-patient ratio requirement that does not compromise the basic needs of residents. CMS researchers have established this ratio to be 4.1 hours per resident day, which is far above the 2.46 hours that facilities in the tenth percentile provide⁷⁷. Second: federal and state provisions are needed to address the alarming rate of staff turnover. Tax incentives can be implemented that reward facilities with high retention rates. The environment of institutions can be improved, and regular staff can be empowered to have more input in decision-making processes. Third: federal training requirements should be increased. Almost all professionals view the 75 hour minimum of OBRA to be inadequate for a profession that is responsible for the needs of a sensitive population. More focus on personal respect, relationship-building, and abuse prevention needs to be implemented in the curriculum, to promote the humane treatment and empowerment of residents.

⁷⁶ Impact of the Affordable Care Act Provisions to Improve Nursing Home Transparency, Care Quality, and Abuse Prevention, The Henry J. Kaiser Family Foundation, January 2013, pg. 11

⁷⁷ Wiener et.al pp.17-18

Increased training requirements means also means that we must increase incentives. As of now, a nurse-aide is a classic dead-end job, with low salaries, poor benefits, and no career ladder.

Social isolation and depression:

Institutions are often perceived as the epitome of social isolation and depression for seniors. There is more than some truth to this opinion: studies of residents of long-term care estimate the prevalence of depression (major and minor) to be as high as 47.4%⁷⁸. Likewise, the prevalence of social isolation has been approximated to be as high as 35% in assisted-living arrangements⁷⁹. These two issues are interconnected with each other, and a range of other health outcomes. Isolation and depression are established risk-factors for heart disease, strokes, cognitive impairment, dementia, and death⁸⁰. Besides these poor health outcomes, institution-imposed isolation denies residents of the most fundamental capabilities that define human life. The need for companionship, social inclusion, attachment, and acceptance are properties that are hardwired into the prefrontal cortices of our brain⁸¹. All the capabilities and positive freedom(s) we hope to protect are based on the principle of social participation, and choosing how one wishes to belong in the world around them.

Multiple characteristics of institutional care conspire together to produce the enormous rates of depression and isolation we observe. One important problem is that institutional care tends to isolate residents from the outside world, and their old social ties. The transition from a home to an institution is a difficult process, since it often entails the loss of old friends, families, activities, and support groups when individuals relocate from

⁷⁸ Mugdha, Thakur and Blazer, Dan. Depression in Long Term Care. Department of Psychiatry and Behavioral Sciences, Duke University MedicalCenter. February 2008.

⁷⁹ Biordi, Diana L. and Nicholson, Nicholas R. The Older Adult and Social Isolation. Jones and Barlett Publishers. 2008

⁸⁰ Ibid.

⁸¹ Cozolino, Louis. The neuroscience of human relationships: Attachment and the developing social brain. New York, NY, US: Norton & Co. (2006)

their old communities⁸². Friends and families tend to remain behind: one in three residents has not received a single visit in a twelve month period⁸³. Zoning laws often distance nursing homes from vital social institutions, such as churches or places of recreation. Access to transportation is limited, due to the budget constraints and insufficient staff endemic to these facilities⁸⁴, cutting off residents from the outside world

The clinical, bureaucratic, and impersonal environment associated with long-term care is the largest factor contributing to the prevalence of isolation and depression. The atmosphere of most facilities resembles that of a medical center, where residents are treated as patients rather than persons. Institutions adopt a problem-oriented approach to care, which focuses on medical treatment and risk prevention. Nurse-aides tend to perceive residents through the impersonal lens of a health worker dealing with medical issues, rather seeing them as individuals with unique social and emotional needs⁸⁵. In some institutions, residents are identified through their specific diagnoses rather than their own names⁸⁶. Administrators design policies and routines without accommodating the preferences of the residents or the staff. Care is standardized without regards to individual care needs and personal desires. The architecture of these institutions reflects a hospital environment: there are few communal areas where residents can socialize or rooms devoted to entertainment⁸⁷. Residents often have little to no control of their own living space, unable to arrange their own furniture and choose their own decorations. Even the walls of most

⁸² Cannuscio, Carolynn, Block, Jason and Kawachi, Ichiro. Social Capital and Successful Aging: The Role of Senior Housing. *Annals of Internal Medicine*, September 2, 2003

⁸³ Robyn Findlay and Colleen Cartwright. Social Isolation & Older People. Australasian Centre on Ageing. 2002.

"[http://www.communities.qld.gov.au/resources/communityservices/seniors/isolation/reports/literature review.pdf](http://www.communities.qld.gov.au/resources/communityservices/seniors/isolation/reports/literature%20review.pdf)"

⁸⁴ Cannuscio, Block, and Kachawi pp. 397

⁸⁵ Ibid.

⁸⁶ Koren, Mary J. Person-Centered Care For Nursing Home Residents: The Culture-Change Movement. *Health Affairs*, 29, no.2 (2010):312-317

⁸⁷ Canuscio, Block, and Kachawi, pp.397

facilities are white or various shades of beige, highlighting the inseparable resemblance of long-term care facilities to medical centers⁸⁸.

The rate of chronic depression for institutionalized seniors with some form of dementia is enormous, estimated to be upwards of 60%⁸⁹. Cognitive decline, mental illness, and isolation go hand-in-hand with the methodical dehumanization endemic to some facilities. The emotional effects of Alzheimer's disease (AD), the most common form of dementia, have been described as "living as a stranger in one's own world"⁹⁰. As the neurological impairment of AD progresses, more and more uncertainties emerge that erode an individual's confidence to interpret their relationships and their life experiences as a coherent whole. These shifting self-identities prompt a range of emotions such as frustration, hopelessness, humiliation, anger, fear, disempowerment, and disconnectedness⁹¹. As an individual afflicted with AD loses his or her own sense of self-perception, their interactions with others and the meanings derived from them begin to define more and more of their self-image⁹². Because the emotional well-being of individuals with dementia is both fragile and interdependent on interactions with caregivers, it is imperative that caregivers acknowledge the unique needs, achievements, talents, and hopes of each resident⁹³. We observe the opposite reaction in most cases: as mental decline advances the personhood of the resident is valued less and less. Facilities that remain focused on an impersonal, mechanistic model of treatment are often incapable of recognizing the importance of personhood. These care models can even become malignant and disabling, if caregivers adopt the common medical stigma that considers those with

⁸⁸ Ibid.

⁸⁹ Late Life Depression: A Fact Sheet

http://www.gmhfonline.org/gmhf/consumer/factsheets/depression_factsheet.html

⁹⁰ Kitwood, T. 1997. *Dementia Reconsidered: The Person Comes First*. Berkshire, UK: Open University Press.

⁹¹ Ibid.

⁹² Penrod et.al 2007. Reframing Person-Centered Nursing Care for Persons with Dementia. *Res. Theory Nurse Pract.* 21(1): 51-72

⁹³ Kitwood, T. 1992. "Towards a Theory of Dementia Care: Personhood and Well-being." *Ageing and Society* 12(3): 269-87.

dementia as personless, inhuman, and a shell of the person who used to be. Subtle and insidious behaviors, such as infantilism, disempowerment, and labeling patients as senile are taken for granted in the rushed, stressful environment of understaffed nursing homes⁹⁴. The negative attitudes and expectations of caregivers, who are focused on the pathological progression of dementia, becomes a self-fulfilling prediction that fuels the depersonalization and disablement of the person dealing with the confused worldview of dementia.

Recommendations for confronting social isolation and depression:

In our current institutional model, seniors are separated from their old communities, and then placed in a dehumanizing environment where values and preferences are an afterthought. If we accept that a comprehensive definition of health includes social and emotional well-being, we must address the factors leading to social isolation and depression.

First: long-term care facilities should support connections to individuals, organizations, and causes outside of its walls. Inclusion and companionship are the most reliable remedies for social isolation⁹⁵. We must avoid restricting residents from vital social institutions, and provide them with real opportunities to participate in the world around them. In practical terms we must devise policies that promote access to transportation, whether this entails public transportation or private staff-based service. The ideal result would be to ensure reliable, on-demand transportation to a number of places such as churches, local senior centers, public facilities, stores, families, and wherever else residents deem valuable. Facilities should also focus on building partnerships with local organizations that can provide cost-effective opportunities for interaction and enrichment. Volunteer programs and charitable organizations are a prime example of a beneficial partnership. Intergenerational programs and educational centers are also valuable sources of

⁹⁴ Penrod et.al pp.9-10

⁹⁵ Biordi and Nicholson, pp. 6-7

companionship and enrichment⁹⁶. These partnerships should be mutual, to the benefit of both parties involved. For example, elders can contribute their own service to volunteer programs partnered with the institution. Educational, social, and entertainment opportunities can be held within the home itself, which are open to the public⁹⁷. Furthermore, local partnerships can provide facilities with essential services that underfunded facilities cannot provide themselves.

The depersonalizing clinical approach to long-term care common in most facilities is a more intricate problem to address. A real solution to this issue necessitates a complete transformation in the attitude, practices, and organizational structure of long-term care facilities. The focus of care needs to be redirected from the institution to the individual. The following section outlines this alternative approach to institutional care, which emphasizes the person as the center of care.

Empowering residents through person-centered care:

An important movement is emerging among care providers called person-centered nursing care, which has been developed to deal with the widespread issues of abuse, isolation, endemic boredom, and learned helplessness in assisted living that have been discussed. This movement focuses on the idea that facilities should not be viewed as health care institutions, but rather as person-centered homes that offer long-term life services⁹⁸.

The overarching goal of the person-centered care movement is to individualize caregiving, making nursing facilities more homelike and less institutional⁹⁹. The movement promotes a set of humanistic principles that caregivers should progress towards, rather than

⁹⁶ Practical Approaches for Building a Resident Centered Culture
<http://www.residentcenteredcare.org/Pages/partthree.html>

⁹⁷ Ibid.

⁹⁸ Koren pp.1

⁹⁹ What is Culture Change? The Pioneer Network,
<http://www.pioneernetwork.net/CultureChange/>

prescribing specific practices or a single all-encompassing model¹⁰⁰. Most of these initiatives do not involve a significant investment of resources, but rather a readjustment in attitude or behavior that empowers residents¹⁰¹. For example, one of the most important steps of culture change is to change the language of long-term care, replacing outdated and depersonalizing clinical language with more person-centered terms. This means, for example, that residents are referred to as friends and neighbors rather than patients, and people are identified based on their capabilities rather than their disabilities¹⁰². Using person-centered language can be as simple as reversing common phrases to put the person first and the characteristic second: for example, a “wheelchair-bound resident” becomes “a person who uses a wheelchair”. The second phrase indicates that a resident is defined through his or her unique personhood, rather than a particular health condition¹⁰³. The Pioneer Network, an advocate group at the forefront of the movement, defines the qualities of a person-centered institution as: resident direction, a homelike atmosphere, close relationships, staff empowerment, and collaborative decision making¹⁰⁴.

Long term studies of institutions that have adopted a person-centered care model have demonstrated promising results, with significant improvements in resident and staff satisfaction¹⁰⁵. These initiatives also produce significant financial gains: implementing culture change in a 140-bed nursing home resulted in additional \$584,073 annual revenue, due to decreased staff turnover and increased resident satisfaction leading to more occupants¹⁰⁶. The positive results of these studies have been replicated throughout a wide range of nursing homes, including controlled studies that compare similar facilities operated

¹⁰⁰ Ibid.

¹⁰¹ Cutler, Lois J. and Kane, Rosalie A. Practical Strategies to Transform Nursing Home Environments. The Pioneer Network, 2004.

¹⁰² The Language of Culture Change
<http://www.pioneernetwork.net/CultureChange/Language/>

¹⁰³ Ibid.

¹⁰⁴ Koren pp.2

¹⁰⁵ Koren pp. 3

¹⁰⁶ Grant LA. Culture change in a for-profit nursing home chain: an evaluation. The Commonwealth Fund. Feb 13 2008

through the same service provider (Green Houses)¹⁰⁷. These studies also demonstrate that culture change does not sacrifice clinical results for resident satisfaction: clinical outcomes and inspection results were equal or better at facilities that had adopted person-centered care initiatives. An example of successful culture change can be found in Lexington, where Donna Gail has adopted a person-centered care model at Heritage Hall. Gail requested that funds used for advertising at Heritage Hall instead be used to create effective enrichment programming for residents, providing much-needed opportunities for social interaction and entertainment. These person-centered initiatives have enhanced the lives of the residents of Heritage Hall, while occupancy levels and profits have not declined¹⁰⁸.

One important theme of the culture change movement is that significant improvements in the environment of a nursing home can occur without major expenditures¹⁰⁹. As demonstrated, a commitment to provide residents with more genuine choice and self-governance can also be practical and cost-effective. Simple behavioral adjustments, such as nurses knocking before entering bathrooms, or asking residents for input on their care routines, can have a profound influence on the quality of life of residents¹¹⁰. Nurses, who are much more in tune with the needs of residents, can be given more influence in decision-making than distant administrators. Institutions can also make small, inexpensive renovations that can offer significant improvements in the living environment for all residents, making the institution feel more like a home than a clinic¹¹¹. For example, researchers concluded that even adding a small amount of color to the environment of most nursing homes can be a major improvement towards a comfortable

¹⁰⁷ Kane RA, Lum TY, Cutler LJ, Degenholtz HB, Yu TC. Resident outcomes in small-house nursing homes: a longitudinal evaluation of the initial Green House program. *JAm Geriatr Soc*. 2007;55(6):832-9.

¹⁰⁸ Tillander, Angelica. Equal Opportunity and the Elderly. Shepherd Program, Washington and Lee U. April 2013.

¹⁰⁹ Cutler and Kane pp.2

¹¹⁰ Ibid.

¹¹¹ Koren pp. 2

home environment¹¹². Nevertheless, the walls of most nursing homes remain various shades of beige, highlighting the limited scope of the culture change movement.

A mere 5% of facilities reported that their environment had been transformed through culture change, while another 10% reported that at least seven or more culture-change practices had been initiated¹¹³. Most nursing homes retain a clinical model, despite widespread public awareness of the person-centered culture change movement¹¹⁴. Several crucial factors, such as staff turnover rates, regulations, scarce resources, and inadequate training conspire together to limit the prevalence of culture change initiatives in nursing homes. Culture change initiatives depend on dedicated leadership that is committed to the well-being of residents, a stable, adaptable staff, and sufficient funding for environment improvements¹¹⁵. Some state and federal regulations are also incompatible with the expanded freedoms of person-centered care. For example, some states forbid nursing facilities to have open kitchens. While this regulation might prevent potential accidents, it also makes residents incapable of obtaining a snack for themselves outside of rigid meal schedules¹¹⁶. The federal inspection process, which has an enormous influence on nursing home behavior, also reinforces an impersonal clinical model for care. Inspectors tend to focus on quality-of-care problems rather than evaluating the overall well-being of residents. In Rhode Island, 90% of care providers believed that the highest priority of each inspection was detecting and eliminating deficiencies in clinical care¹¹⁷.

Recommendations for implementing person-centered care:

The regulation and inspection process exerts enormous influence on institutional behavior: nursing homes model their practices around the goal of producing the best

¹¹² Cutler and Kane pp. 4

¹¹³ Koren pp. 4

¹¹⁴ Ibid.

¹¹⁵ Ibid.

¹¹⁶ Ibid. pp. 5

¹¹⁷ Stevenson DG, Gifford DR. Is nursing home regulation a barrier to resident-centered care? J Am Geriatric Soc. 2009;57(1):183-5.

inspection results possible¹¹⁸. As long as the rhetoric of regulations and inspections emphasizes clinical data, facilities will continue to focus on practices that produce favorable statistics regardless of the freedom or well-being of their residents. For widespread culture change to occur, we need to re-evaluate the priorities of federal regulations and inspections. While the health of residents cannot be compromised, regulations should be more conducive to innovation and resident independence¹¹⁹. Federal and state inspection forms should include more measures that evaluate whether facilities honor resident rights and independence¹²⁰.

State initiatives to integrate person-centered care into regulations and inspections have proven successful thus far. The Rhode Island Department of Health implemented provisions in its annual recertification inspection process to promote resident-centered activities¹²¹, as part of an initiative named the Individualized Care Pilot. Supplemental questions were included in the inspection that focused on whether resident preferences were met, and whether facilities were engaged in broader initiatives to improve the life of residents. Inspectors were also required to participate in 20 hours of training familiarizing them with resident-centered care practices and attitudes¹²². These provisions resulted in significant increases in resident access to elements of person-centered care. Forty-three percent of residents reported an improvement in their independence, and 64% of residents reported being more involved in decision-making¹²³. Despite promising results, the occurrence of initiatives supporting resident-centered care is rare. The 2010 ACA endorses

¹¹⁸ Ibid.

¹¹⁹ Ibid.

¹²⁰ Koren pp. 5

¹²¹ Stevenson, David G. and Gifford, David R. The Impact of a Regulatory Intervention on Resident-Centered Nursing Home Care: Rhode Island's Individualized Care Pilot. The Commonwealth Fund, December 2010.

¹²² Ibid.

¹²³ Ibid.

the idea of culture change, and has outlined two national projects to support resident-centered care. However, no funding has been issued to implement these initiatives¹²⁴.

Providing access to effective activities:

A full range of access to a broad range of stimulating activities is an important hallmark of a distinguished long-term care institution. Residents often lead lives that lack engagement and purposeful activities, leading to increased levels of agitation, aggression, and depression¹²⁵. Ensuring that opportunities are available for stimulating enrichment is an important consideration, as a part of the authentic freedoms that Sen and Nussbaum outline. Nussbaum points out that being able to use imagination and thought in connection with experiences of one's own choosing is an essential human right¹²⁶. What kind of programs should facilities provide to engage residents with enriching activities?

Research has demonstrated that the best solution is to ask the residents themselves. Numerous studies have proven that tailoring all forms of stimulus to the preferences of participants results in significant increases (ranging from 91-133%) in both engagement length and cognitive development¹²⁷. It is an unsurprising result that self-determination is an essential element of satisfaction. These studies also indicated that the most effective activities were both goal-directed¹²⁸ and guided¹²⁹.

¹²⁴ Implementation of Affordable Care Act Provisions to increase Nursing Home Transparency, Care Quality, and Abuse Prevention. *The Henry J. Kaiser Family Foundation*. (2011)
<http://www.kff.org/medicare/upload/8406.pdf>

¹²⁵ J. Cohen-Mansfield, M. S. Marx, K. Thein, and M. Dakheel-Ali, "The impact of stimuli on affect in persons with dementia," *Journal of Clinical Psychiatry*, 72(4): pp.480-486. 2011

¹²⁶ Nussbaum 2011 pp. 11

¹²⁷ Leone, Elsa, Deudon, Audrey, Piano, Julie, Robert, Phillipe, and Dechamps, Arnaud. Are Dementia Patient's Engagement Using Tailored Stimuli the Same? *The Apathy Dilemma in Nursing Home Residents*. *Current Gerontology and Geriatrics Research*, 2012

¹²⁸ J. Cohen-Mansfield, K. Thein, M. Dakheel-Ali, N. G. Regier, and M. S. Marx, "The value of social attributes of stimuli for promoting engagement in persons with dementia," *Journal of Nervous and Mental Disease*. 198(8): pp.586-592. 2010

¹²⁹ Leone et.al pp.6-7

A sense of purpose and direction, and the creation of enduring values (such as art, knowledge, and experiences) are important attributes of valuable activities¹³⁰. Activities must also be compatible with capabilities of each resident, maintaining a good balance between the challenges of the task and the abilities of the resident. Residents should feel challenged, but also feel confident in their abilities to complete the task at hand¹³¹. These conditions help individuals achieve *flow*, a concept that describes a feeling of full immersion, engagement, and control over a valuable task¹³². The attainment of flow is an important precondition to deriving authentic happiness from activities.

Finding the proper balance between challenge and resident capabilities in activities is a difficult task for most facilities. Vast differences in functioning can exist between different individuals in the same nursing home, making individual activities impossible for some and too simple for others¹³³. This issue poses an enormous barrier to us in our efforts to provide effective, all-inclusive programming for residents of the Manor. BINGO, our most established program there, provides effective stimulus for a miniscule fraction of the residents that participate. Residents with significant mental disabilities find BINGO to be impossible. In other cases, more high-functioning residents perceive BINGO as childish and unstimulating. The apparent solution to this dilemma is to provide broad access to multiple levels of different activities, to avoid neglecting the opportunities of each group. This is quite difficult in practical terms, as most facilities lack the staff and resources to provide a broad range of activities. In this situation, facilities must turn to outside agencies for assistance, economize, or be provided with more resources.

¹³⁰ M. Csikszentmihalyi. *Finding Flow: The Psychology of Engagement with Everyday Life*. Basic Books, New York, NY, USA, 1997.

¹³¹ Ibid.

¹³² Ibid.

¹³³ Cohen-Mansfield et.al

Conclusion:

America has failed all of its promises to institutionalized elders. We have failed to provide the highest practicable level of well-being that was promised in the 1987 OBRA. We have also failed to protect the American ideals of freedom and equal opportunities, promised in our founding documents. In some cases, we have even failed to protect the basic human dignities of residents. Furthermore, we are quite aware that these failures exist. Hundreds of reports issued to federal oversight agencies repeat the same problems and recommendations: residents need more protection from mistreatment, more access to staff and transportation, more personal freedom, and more real opportunities to live a full life. We have a clear need for reform, as well as a comprehensive set of effective initiatives that could improve the lives of residents.

The development of OBRA 1987 was a notable representation of how cooperation between consumer advocates, researchers, and the government can improve the nature of policies. Researchers identified and reported serious care deficiencies, advocates represented the disempowered residents, and politicians listened to the recommendations of these parties. We find ourselves once again at another critical moment, where the nation must choose whether it will protect the well-being of its elders. This time however, the scope of institutional care is far more extensive. Institutional reform will be a difficult process, one that will incur significant costs before comprehensive improvements can be made. Nevertheless, if we value our elders as full human beings, we also have an obligation to protect the capabilities and liberties that are essential to a dignified life.

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http://www.pnf.org/Definitions_of_Health_C.pdf
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