

AN ETHICAL ANALYSIS OF IN-HOME HEALTH COVERAGE BY ILLINOIS'S MEDICAID PROGRAM

Introduction:

In-home health services are a benefit for many Social Security Disability Insurance (SSDI) beneficiaries in state Medicaid programs. For the physically disabled population, the ability and decision to live in the community can be integral to maintaining a meaningful and productive life. This paper seeks to analyze how considerations of cost can impact beneficiaries' autonomy and whether such decisions differ when the beneficiary has reduced autonomy due to physical disability. Analyses of ethical issues are complex by design; state actors must make hard choices on a daily basis, but this does not mean that the resolutions they develop should be acceptable based on the difficulty in decision-making. Only by comparing specific State actions to ethical principles--such as respect for autonomy, beneficence, and justice—can potentially improper State action be judged fairly. These principles have been outlined in The Belmont Report and Beauchamp & Childress's *Principles of Biomedical Ethics*¹².

Although the two ethical analyses were developed as research and clinical guidance for ethical treatment, they combine universal and normative beliefs similarly to the confluence of the issues addressed here. In regards to Medicaid coverage, a decision to change or exclude a preexisting benefit is perceived more severely by the beneficiary than the governing body overseeing that benefit. While not directly human subject research or clinical care, understanding how normative beliefs impact value-laden decisions inherently guides policy development.

¹ The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. 1979. The Belmont Report. Retrieved December 5, 2014, from <http://www.hhs.gov/ohrp/policy/belmont.html>

² Beauchamp, Tom L., and James F. Childress. 2013. *Principles of biomedical ethics*. n.p.: New York : Oxford University Press, c2013., 2013. Himmelfarb Health Sciences Library Catalog, EBSCOhost).

Determinations of benefit coverage vary between state Medicaid programs³. While benefit decisions are a state matter, the inclusion of cost as a condition for certain benefits may fluctuate between states in their acceptability and appropriateness⁴. To that end, consider the following scenario: A young woman has been physically disabled since birth. She receives SSDI benefits from her state's Medicaid program, but she is capable of rational thought (meaning that she does not have a legally-defined mental disability). Her parents have served as her primary caregivers, and the state has provided in-home health services as part of her benefit package. However, one of the girl's parents died and the other is no longer able to lift the girl, who is over the age of 21. In determining whether to offer a more robust package of in-home health services, the state considers the cost to the state of in-home health care in comparison with care in a nursing facility. The final decision of where the fully-cognizant girl will be allowed to live with the support of the state Medicaid program lies with the state's Medicaid program, not with the girl or her family, regardless of the girl's input. This situation may seem extreme, but recent changes to the Illinois Medicaid program resulted in this exact scenario.

In the state of Illinois, a person with a physical disability seeking Medicaid SSDI in 2014 must meet the following requirements: U. S. citizen or legal alien; Resident of the State of Illinois; Under age 60 at time of application; Medicaid eligible or enrolled in the Health Benefits for Workers with Disabilities program; Medical determination of a diagnosed, severe disability, which is expected to last for 12 months or for the duration of life; Be at risk of nursing facility placement as measured by the Determination of Need (DON) assessment; Estimated cost to the State for home care is less than estimated cost for institutional care; Can be safely maintained in

³ LeBlanc, A. J., Tonner, C., & Harrington, C. (2001). State Medicaid programs offering personal care services. *Health Care Financing Review*, 22(4), 155–73.

⁴ Beauchamp, Tom L., and James F. Childress. 2013. *Principles of biomedical ethics*. n.p.: New York : Oxford University Press, c2013., 2013. Himmelfarb Health Sciences Library Catalog, EBSCOhost.

the home or community-based setting with the services provided in the plan of care⁵. From these requirements, there are need-based waivers to allow home and community-based care, and there are different requirements for each category of Medicaid services based on the waiver for those services. Here, the focus is on the Medicaid Home and Community-based Services waiver (DHS 4243 waiver)⁶.

In June of 2012, the Illinois Department of Healthcare and Family Services released an informational notice explaining changes to the state's Medicaid program. Specifically, it explained that Governor Pat Quinn had signed Public Act 097-0689 (dubbed the SMART Act) into law⁷. This implemented a series of policy changes into the Illinois Medicaid program, including a requirement specifically for waiver programs for home and community-based care. When new applications for home and community-based services waivers are reviewed initially or during an annual eligibility determination performed by the Department of Human Services, resource reviews must be conducted by the Office of the Inspector General⁸. This is the formal addition of cost as a consideration for home health benefits.

In the context of this analysis, physical disability does not include clinically-proven mental illness. The disabled population is capable of lucid thinking and desires to be free and independent, not viewed as a financial burden to the state. Like other rationally-thinking people,

⁵ "Persons with Disabilities." Illinois Department of Healthcare and Family Services. <http://www2.illinois.gov/hfs/MedicalPrograms/HCBS/Pages/disabilities.aspx>.

⁶ State of Illinois. (n.d.). Home Services Program-DHS 4243. Department of Health. Retrieved from <http://www.dhs.state.il.us/page.aspx?item=36737>

⁷ Eagleson, T. (2012, June 29). Coverage Changes Resulting from the Save Medicaid Access and Resources Together (SMART) Act. Illinois Department of Healthcare and Family Services. Retrieved from <http://www.hfs.illinois.gov/assets/062912n1.pdf>

⁸ Eagleson, T. (2012, June 29). Coverage Changes Resulting from the Save Medicaid Access and Resources Together (SMART) Act. Illinois Department of Healthcare and Family Services. Retrieved from <http://www.hfs.illinois.gov/assets/062912n1.pdf>

independence offers decision-making to lead a free and fulfilling life⁹. For many people with physical disabilities, there is no need for rehabilitative care due to the permanent or degenerative nature of their diseases¹⁰. However, maintenance of care is still integral to the person's well-being, and caregivers and home health nurses and aides allow for that maintenance in the person's own home.

Context:

What compels a state to desire cost-neutrality in its entitlement programs? The answer is complex and multifaceted. To start, benefit changes are federally mandated to be cost-neutral (in the absence of specific legislation) to maintain the integrity and viability of state programs¹¹. Additionally, there are fears of the woodwork effect, which is a policy term for the insurance concept of moral hazard. This means that, in the state's perspective, if too many people sign up for coverage and benefits without an increase in the state's revenues, it will not be long before the state experiences cost overruns in its budget¹².

The beliefs of this analysis hinge on the notion that having reduced autonomy via physical disability is different than other variances between individuals. This is not a Rawlsian belief that difference requires making policies for the least among members of society, but rather that treating home health and MRIs in the same way is inconsistent with the ideals that society should uphold¹³. An MRI is a diagnostic tool with life-saving capabilities; home health services are ways of existing in a meaningful way. Home health is not a diagnostic tool or test, and therefore, it must be considered by the state of Illinois in a different light. Even with budget

⁹ Fox, M., & Kim, K. (2004). Evaluating a Medicaid home and community-based physical disability waiver. *Family & Community Health*, 27(1), 37–51.

¹⁰ *Ibid.*

¹¹ Thomas, K. S., Keohane, L., & Mor, V. (2014). Local Medicaid Home- and Community-Based Services Spending and Nursing Home Admissions of Younger Adults. *American Journal of Public Health*, 104(11), e15–e17.

¹² *Ibid.*

¹³ Wenar, Leif, "John Rawls", *The Stanford Encyclopedia of Philosophy* (Winter 2013 Edition), Edward N. Zalta (ed.), from <http://plato.stanford.edu/archives/win2013/entries/rawls/>.

constraints, it is incorrect to view a person's existence as a lifestyle choice because of convenience to the State.

Cost of services in Illinois—and other states—has been a recurring issue. In 2012, there was a funding shortfall in the state accounting for a \$2.7 billion loss for Fiscal Year 2013. This required immediate action to work with state and federal departments to cut costs to return to a budget-neutral program. A compounding factor here is the aging population in Illinois, which means more elderly people will be getting sicker and require Medicaid benefits in addition to their Medicare benefits¹⁴. Between that and the Medicaid Expansion of the Patient Protection and Affordable Care Act (ACA), the population likely to receive benefits from the state program is rapidly increasing. Due to concerns of increased churning from a larger population of beneficiaries, the state must find ways to reduce its overall costs of providing Medicaid benefits¹⁵. As such, considering cost for benefits remains a practical challenge.

While the policy implications of cost-neutrality are important, they are often factors in situations that do not directly involve a person's autonomy¹⁶. The ethical principles of The Belmont Report, which outlines principles for ethical research with human subjects, expand autonomy into two categories of respect for persons: acknowledging individual autonomy and protecting those with diminished autonomy¹⁷. Because the physically disabled need assistance with at least one “activity of daily living”—the basic tasks of everyday life such as bathing,

¹⁴ Laplante, M. P. (2013). The Woodwork Effect in Medicaid Long-Term Services and Supports. *Journal of Aging & Social Policy*, 25(2), 161–180. doi:10.1080/08959420.2013.766072

¹⁵ Sommers, B. D., & Rosenbaum, S. (2011). Issues in Health Reform: How Changes in Eligibility May Move Millions Back and Forth between Medicaid and Insurance Exchanges. *Health Affairs*, 30(2), 228–236. doi:10.1377/hlthaff.2010.1000

¹⁶ Fox, M., & Kim, K. (2004). Evaluating a Medicaid home and community-based physical disability waiver. *Family & Community Health*, 27(1), 37–51.

¹⁷ The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. 1979. The Belmont Report. Retrieved December 5, 2014, from <http://www.hhs.gov/ohrp/policy/belmont.html>

eating, dressing, or transferring—their autonomy is, arguably, reduced¹⁸. There is a necessary dependency on another person or a mechanism to allow that person participation in daily activities, thereby creating a sense of reduced autonomy for the individual¹⁹. Despite this approach to individual treatment, the state also has a moral obligation to the entire population to run a program within its means. Although the population that it serves may be medically needy, all parties will suffer if the revenues are not large enough to meet the projected expenditures.

The previously discussed components of independence are policy-driven concerns for individual autonomy; however, there are ethical concerns that do—and should—impact decision-making regarding benefit determination. For instance, determining whether a certain diabetes treatment should be covered by state Medicaid funds may include a consideration of the cost to the state for providing that treatment. While it may impact a group of beneficiaries if the diabetes treatment is not covered, there would still be other treatments to accomplish the same medical goals. The impact on a person with reduced autonomy is not necessarily the same since there may not be alternatives that maintain the person’s independence; the alternative is institutionalization, which results in a highly different life experience than home and community-based care²⁰. As such, the moral quandary of including cost as a factor for benefit must be analyzed further.

An additional aspect of the scenario with the physically disabled girl is that of the individual’s role in her own care. Just because a person is physically disabled does not mean that

¹⁸ Wiener, Joshua, Raymond Hanley, Robert Clark, and Joan Van Nostrand. 1990. “Measuring the Activities of Daily Living: Comparisons Across National Surveys.” *Journal of Gerontology: Social Sciences* 45 (6): S229–37.

¹⁹ *Ibid.*

²⁰ Thomas, Kali S., Laura Keohane, and Vincent Mor. 2014. “Local Medicaid Home- and Community-Based Services Spending and Nursing Home Admissions of Younger Adults.” *American Journal of Public Health* 104 (11): e15–17.

the person has lost all of her rights²¹. When considering what type of care is best for a person—community-based with family and home health services or institutional care—state decision-makers often forget that the beneficiary also has opinions about the course of care that she is to follow. Physical disability benefits are ordered by providers based on medical necessity; as such, they should be treated like other medical decisions where the patient can influence her own course of care²². To discuss in-home health services requires a respect for the individual so that determinations are made with respect to both individuals and state priorities.

Ethical Impacts:

By defining what is right for the beneficiary and what is practical for the state, there is more at stake than benefit determinations. How the decision is made matters, especially in how that decision impacts individual autonomy. The beneficiary who has lost her primary caregiver and is awaiting a state determination of whether or not home health services will be provided is at the mercy of the state. Does being physically disabled exert a dependency on the state? It appears so, especially in regards to how benefits are dispensed. However, does that dependency remove the girl's rights? Practically, a blanket determination is easier than making case-specific decisions for whether home-health can be continued. Morally, it seems that doing what is best for each beneficiary in each situation is preferable. But in a world of limited resources, broad policies seem to dominate. This effectively creates a scale where equity is valued over equitable care.

In this scenario, the girl is capable of rational thought. That means that the physical disability does not prevent her from contributing to society. She could hold a job that is

²¹ Fox, M., & Kim, K. (2004). Evaluating a Medicaid home and community-based physical disability waiver. *Family & Community Health, 27*(1), 37–51.

²² State of Illinois. (2011, February). Handbook for Home Health Agencies. Illinois Department of Healthcare and Family Services. Retrieved from <http://www2.illinois.gov/hfs/SiteCollectionDocuments/r200.pdf>

accessible to her abilities, as well as interact with the community's economy and spur economic growth. Furthermore, she can contribute in non-economic terms to the well-being of her community and family. These traits are the same as a physically-able-bodied person. To treat her differently simply because of her disability could be viewed as an unreasonable accommodation by the standards of the Americans with Disabilities Act²³. Just because someone requires assistance to complete tasks should not alter what is normative; rather, the ability to complete the same responsibilities must be treated as judged on its own merits.

This example delineates two seemingly competing objectives from policies surrounding the physically disabled: The policy objective is to concurrently increase quality and decrease the cost of services while the ethical objective is to promote social justice and empower individuals with reduced autonomy. Illinois operates with a system where there are limited funds, so trying to understand the minimal level of care that the state must provide is difficult when considering autonomy and social justice.

To elaborate on this, those that do not object to cost being a factor in home health service determinations argue that the state must provide some type of care, but since it is a form of welfare, the beneficiaries do not get to choose what service best fits their needs. This viewpoint contends that welfare, as a gift to those who have a physical disability, have no choice or do not need a choice from the government entities involved with their decision-making. It might be sad that the physically disabled girl cannot get everything she wants, but is it truly unfair? What this viewpoint misses is that the role of government intervention in a person with reduced autonomy's life is not to provide the bare minimum. If the girl needs a wheelchair to survive, is

²³ *Americans with Disabilities Act of 1990*. One Hundred and First Congress: S. 933.
<http://www.dol.gov/ofccp/regs/statutes/ada.htm>.

the government's role simply to make the least expensive wheelchair option available to her/her family, and then let them figure out whether that chair fits their home, vehicle, and other practical needs? If the government provides a single option (institutionalized care), has it met its obligation to those with reduced autonomy and increased dependence on a non-self-actor? This is not to say that limited budgets do not create burdens for decision-makers, but that society has moved past a standard of providing minimal services and calling it good enough²⁴. This analysis of the environmental scan of long-term supports and services by the Center for Health Care Strategies was developed through interviews with state health department leaders and state health policy makers, so the derived data provides insight into the beliefs and practices of the states themselves.

Ethical Standards:

There are specific criteria that should dictate a decision where a Medicaid beneficiary's autonomy is at risk. These standards, as explained in The Belmont Report, include respect for persons, beneficence, and social justice. These must all be analyzed in the context of a limited budget and financial constraints. By setting forth criteria for comparisons, decision-making around whether benefits impacting autonomy can be altered can be more standardized. Each type of care will be analyzed according to these standards in relation to the individual.

Institutional Care:

The care provided in institutional settings is important, and it provides care to over 58% of the population requiring long-term care²⁵. There are diseases, illnesses, and conditions that

²⁴ Engquist, G., Johnson, C., & Johnson, W. C. (2010, May). Systems of Care: Environmental Scan of Medicaid-Funded Long-Term Supports and Services. Center for Health Care Strategies, Inc. Retrieved from http://www.chcs.org/media/LTSS_Environmental_Scan.pdf

²⁵ Fox, M., & Kim, K. (2004). Evaluating a Medicaid home and community-based physical disability waiver. *Family & Community Health*, 27(1), 37–51.

require monitoring and treatment to occur at all times, often with specialized equipment. It is in the interests of the individual to have those services available.

In regards to respect for persons, institutional care plays a conflicting role. If the person selects institutional care him/herself, then it appears as though the person made an autonomous choice to be there and receive care in that setting based on his/her needs. If personal input was not provided or considered, the individual seems to have ceded his/her autonomy. For a population that has reduced autonomy, State actors should not *assume* that they are incapable of self-determination. If that occurs, a decision that is destructive to both autonomous decision-making and respect for those with reduced autonomy occurs. The Belmont Report even explains that “The extent of protection afforded [by the government] should depend upon the risk of harm and the likelihood of benefit. The judgment that any individual lacks autonomy should be periodically reevaluated and will vary in different situations”²⁶. This means that institutional care has great potential to be abused, which should cause individuals to be worried and vigilant.

Beneficence comes from the notion of doing no harm to the individual and maximizing possible benefits while minimizing harms. Institutionalization seeks to monitor the individual, and thus reduce harms. However, long-term care in a nursing home is not a remedial source of care; rather, the idea is to maintain care and give a sense of independence. This means that while harms are minimized, there is very little action to maximize benefits to the individual. If that were the case, why would individuals share rooms with others in a place where infections can be transferred so readily between people with weaker immune systems²⁷? Therefore, only half of the goal of beneficence is upheld for individuals in institutions.

²⁶ The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. 1979. The Belmont Report. Retrieved December 5, 2014, from <http://www.hhs.gov/ohrp/policy/belmont.html>

²⁷ Thomas, K. S., Keohane, L., & Mor, V. (2014). Local Medicaid Home- and Community-Based Services Spending and Nursing Home Admissions of Younger Adults. *American Journal of Public Health, 104*(11), e15–e17.

Justice refers to the allocation of resources and who bears the burdens of such distributions. The goal is to ensure that each person receives what he/she is entitled to, without exploiting a particular population due to convenience. Due to the many definitions of justice, The Belmont Report synthesizes this principle into addressing one or more of the following principles: justice is giving each person an equal share, or justice is giving each person according to his/her individual needs, or justice is giving to each person according to his/her individual effort, or justice is giving to each person according to social contribution, or justice is giving to each person according to his/her merit²⁸. Therefore, justice here requires the physically disabled to be helped by the care programs developed, and that the programs do not show a bias towards one program over another.

In the case of institutional care, an argument for justice can be maintained. Social distribution of justice principles shows that giving everyone an equal share of the available resources is a form of justice, and here, it appears to be upheld. If someone needs institutional care, that is available. By treating the physically disabled population as a community, all members have access to the same location of care services, even if it is not individually ideal. This, in effect, is a form of justice.

Home Health & Community Services:

Despite the impacts of institutional care on convenience to the State, home and community-based service can provide more fitting care to a segment of the population. A 2012 study by Sands et. al. concluded that, when young, disabled people received more hours of paid

²⁸ The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research. 1979. The Belmont Report. Retrieved December 5, 2014, from <http://www.hhs.gov/ohrp/policy/belmont.html>

home health care services they were less likely to transition to nursing homes²⁹. In fact, in this randomized and controlled study, the closer the number of hours of home health services approached 24 hours/day, the less likely physically disabled people were to seek nursing home services³⁰. Multiple studies also conclude that the cost of home health services is less than nursing home care³¹. Therefore, making an investment in more home health services actually can lead to decreased costs.

In terms of respect for persons, home and community-based services are more likely to uphold standards of self-determination in daily living, as the individual remains in his/her home. Even with aides and nurses, the decision-making activities are those of the individual, so there is inherent respect for the individual's autonomy. Relating this to the principle of protecting those with diminished autonomy, this source of care operates under the belief that protection does not mean stepping into the shoes of the physically disabled. State officials should seek input of the affected communities, but it is even more important that they protect the autonomy of those with diminished autonomy to allow them to make decisions in the face of opposition. This shows more respect to the individual, is much less prescriptive, and treats the physically disabled like other members of society, which they are.

The concept of beneficence applies here by seeking to secure the well-being of the physically disabled individuals. Beneficence is an interesting standard, as it inherently applies to the individual but also requires an action by the State. To be beneficent, a policy must recognize the long-term risks and benefits of a particular action, and such a response should be in the

²⁹ Sands, L. P., Huiping Xu, Thomas III, J., Paul, S., Craig, B. A., Rosenman, M., ... Weiner, M. (2012). Volume of Home- and Community-Based Services and Time to Nursing-Home Placement. *Medicare & Medicaid Research Review*, 2(3), E1–E20. doi:10.5600/mmrr.002.03.a03

³⁰ *Ibid.*

³¹ Thomas, K. S., Keohane, L., & Mor, V. (2014). Local Medicaid Home- and Community-Based Services Spending and Nursing Home Admissions of Younger Adults. *American Journal of Public Health*, 104(11), e15–e17.

interests of the physically disabled person. Home and community based services seek to do no harm and maximize benefits to the individual. It is possible, however, that some decisions to receive care in a particular location could be biased for or against institutional care, and ethical decisions should be made devoid of internally held biases. Despite this, it is important to note that beneficence is generally upheld by this care option.

Finally, the analysis surrounding home health and justice shows that it is better to look at the population from an individual need perspective rather than as a singular community. Home health prioritizes individual needs over community needs since the care provided occurs in a way that inherently values independence for the physically disabled. The principle of justice cannot be biased, and including more than one option is an effective way to counter bias towards having a singular option for care. This relates to arguments about treating physical disability as a diagnostic test rather than a form of existence. Claiming that all people receive the same minimal level of care (e.g. institutional care which places the physically disabled in a setting that allows State actors or medical personnel greatest ease in dispensing treatment) ignores the differences in individual needs. Cost should not be a factor in determining the guiding principles of a system that automatically incorporates competing interests for action, and the objectives of State action should be *compared to cost*, not analyzed as a *factor of cost*.

Discussion of Autonomy and Policy

With these ethical standards in mind, consider how both a person with a physical disability and a state Medicaid agency should proceed. Home health services are focused on the individual and his/her needs, and study after study has proven its cost-benefit indications³². Therefore, the level of care provided is above the level of care from nursing facilities in that

³² Engquist, G., Johnson, C., & Johnson, W. C. (2010, May). Systems of Care: Environmental Scan of Medicaid-Funded Long-Term Supports and Services. Center for Health Care Strategies, Inc. Retrieved from http://www.chcs.org/media/LTSS_Environmental_Scan.pdf

respect. However, institutionalized care facilities allow for quicker interaction with care professionals, many of whom are on staff or on-call for the facility. The required accreditation reveals more scrutiny for institutionalized care, so the practitioners are more likely to have been trained more rigorously to adapt to specific scenarios. Additionally, home health nurses and aides tend to be younger, so their exuberance for helping people may not equate to their skill at their profession³³.

Finally, the desires of the individual must be taken into account. If their conditions allow it, home health services are preferred since it allows individuals to remain integrated with their families and communities³⁴. Therefore, home health services as a policy decision reflect two of the three ethical criteria for analysis, compared to the training and expertise of institutionalized care. By defining autonomy in the context of this policy decision to consider cost, it is important that the state of Illinois not limit access to home health services because it deems its financial interests more important than the criteria outlined above. Cost matters, but creative thinking can allow for a more adaptive and meaningful approach.

Conclusion

The autonomy of the physically disabled individual is of the utmost importance; both the individual and the state have an interest in protecting that person's rights and freedoms. However, the constraints of budgetary battles have caused home health benefits to be threatened in certain states. The fact that there is little in the current body of research knowledge about this situation suggests that the public agrees with the state's responses due to the budget constraints,

³³ Cohen, M. A., & Tumlinson, A. M. (1997). Understanding the State Variation in Medicare Home Health Care: The Impact of Medicaid Program Characteristics, State Policy, and Provider Attributes. *Medical Care June 1997*, 35(6), 618–633.

³⁴ Cohen, M. A., & Tumlinson, A. M. (1997). Understanding the State Variation in Medicare Home Health Care: The Impact of Medicaid Program Characteristics, State Policy, and Provider Attributes. *Medical Care June 1997*, 35(6), 618–633.

or that the current definition of justice is a community-based approach which disregards individual protections and does not respect individual autonomy. Cost-neutrality is important, but ethically, a person's life matters more than a politicized budget. The significance of this decision should not be lost, and the conversation must continue to develop policies more amenable to all parties.