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### The Medical Industrial Complex: Nursing Homes and Care Facilities

The medical industrial complex model describes the health care system and related organizations, like insurance companies, government programs, prisons, and long term care facilities, as profit driven systems which disenfranchise historically marginalized groups by design (Mingus “Medical”). The disabled community has an extremely complex relationship with the medical industry, the lived experience of which varies significantly from person to person depending on the specifics of their disability and other axes of their identity such as economic status, race, ethnicity, gender, and many others. There are two million people with disabilities in the United States who rely on Medicaid to fund their care needs who are currently placed in nursing homes and other care institutions (“Housing”). Doing so reduces their agency over their lives to almost nothing and secludes them from society, having very negative impacts on their quality of life. There are alternatives to institutionalization that are covered by Medicaid, but unfortunately they continue to be difficult to access.

People with disabilities have different levels of involvement and engagement with the medical industrial complex depending on their medically perceived needs and personally perceived needs. In some cases, such as Mia Mingus, who rejected the painful treatments and leg braces ordered by doctors, the complex acts solely as an actively harming party trying to fix a disability that is in a reality a healthy difference (Mingus “Disability”). But for others, who need

care and assistance doing daily tasks, and financial assistance from the government to get access to these privileges, the medical industrial complex, while undeniably harmful, offers some benefits by being a means to access needed resources. Care facilities like nursing homes provide these services for many disabled adults with Medicaid footing the bill. However there are also a slew of personal testimonies from institutionalized adults with disabilities who wish to leave these institutions but are effectively trapped by the lack of financial support to access the care options they desire — most of which include people returning to their own homes and lives before institutionalization.

There are lots of testimonies of disabled adults with varying degrees of paralyzation that were acquired in adulthood due to various accidents. One example of many is Adam Martin, who has lived in a nursing home in South Dakota since becoming quadriplegic at only 25 years old (Sedensky). He goes to physical therapy most days and receives assistance with daily personal care tasks, although the help is based around the busy schedules of the nursing home employees. Martin's family is unable to take care of him, and he is reliant upon Medicaid to financially cover his care expenses. Mariussi Ogando-Rodriguez has lived in a nursing home for 3 years even though she is capable of caring for herself because she requires dialysis 3 times a week (Thomas, Fink, and Smith). She could very easily live outside of an institutionalized setting, but the Medicaid funding she receives requires her confinement. A common fault of nursing homes mentioned across these testimonies are that nursing homes are depressing environments for young people. They feel isolated being surrounded by people significantly older than them, and living in an institution designed for those older people does little to keep them engaged and entertained. Furthermore, the lack of privacy and proximity to death is very upsetting.

Ogando-Rodriguez says that living in a nursing home is a source of desperation (Thomas, Fink, and Smith).

The medical industrial complex does not only drive disabled people into nursing homes through Medicaid, but also through “hospital discharge planners” where being institutionalized in a care facility is considered a required step for being released from the hospital and eventually to home (Johnson). And once in a care facility, it can be very difficult to leave due to a lack of realistic alternatives according to Patrick Hackney, a disability rights attorney (Cleek).

The effects of the medical industrial complex on disabled people are not felt equally along class lines. For example, Harriet McBryde Johnson, who lived independently with a neuromuscular disease for her entire life, was able to avoid living in a nursing home since she was financially well off. Even though she had more extensive care needs than some of the sources of the aforementioned testimonies, she avoided institutionalization by hiring her own care providers out of pocket, since she had the financial means to do so (Johnson). But she too feared that would not always be the case, since she recognized that her freedom was a direct result of her wealth, and without it she too could have been living in a nursing home.

Tetraplegic Paul Boyd has experienced the transition from home care to institutionalized living. For the first 10 years of being disabled, he lived at home and was cared for by his family members (Cleek). But when they became unable to continue caring for him, they placed him into a nursing home against his will. Boyd is marginally lucky in that he regularly gets out of the institution to attend graduate school classes, but he still suffers the negative effects of isolation from his peers as a result of living in a nursing home. Without the financial resources to hire

outside help and/or without family members willing and able to provide care, institutionalization becomes the reality for many people with disabilities.

It is important to note that the care needs of elderly and disabled people can overlap and this is one of the reasons why nursing homes become the residences of disabled adults throughout the United States. The distinction between elderly and disabled statuses is not always a very clear one. Rather, elderly often serves as a euphemism for both old and disabled, so in many ways the criticisms of the nursing home complexes expressed by younger disabled adults are equally applicable to the experiences of the elderly who also live in these institutions, particularly the closeness of death and the lack of privacy and agency.

The institutionalization of younger people is a surprisingly common occurrence. Approximately 15% of all nursing home residents are less than 65 years old, and while these residents are not all disabled, the vast majority of them are (Sedensky). That is a total of about 210,000 younger people who are spending their lives institutionalized, many of whom desire to be in their homes instead (Thomas, Fink, and Smith). There are lots of people who likely would do well with a home based care system compared to being institutionalized. These individuals are of working age and/or only require care at certain times in the day, such as for wake-up and bedtime routines (Thomas, Fink, and Smith). For instance, with at-home care providers present at those times of the day, there are many adults with disabilities who can and do have healthy, fulfilling lives at home. But to this day, the medical industrial complex is still trapping most of these individuals within the care facility system as a means to keep government funding flowing through the nursing home industry.

As a result of *Olmstead vs. L.C.*, the government is required to provide funding for at-home or community based care when that amount of care is appropriate for a patient's disability rather than effectively forcing institutionalization by having it be the only means of receiving both care and financial support (Pear). Alternatives are supposed to be offered to people with disabilities living in "state institutions, intermediate care facilities for the mentally retarded, nursing facilities, psychiatric hospitals and residential service facilities for children" as well as people currently living at home whose disability may cause them to be institutionalized in the future (Pear). Since 2000, state Medicaid programs have been required to offer some ways to support at home care (Pear).

However, the financial resources for at-home care are not easily accessible, both because of the multitudes of hoops to jump through, the difficulty of navigating these hoops from within the institution, and the slowness of the process. In practice, home based healthcare programs fall short of federal expectations with waivers for at-home care still being rarely issued. In Alabama, only 19 people received this kind of financial aid between 2011 and 2013, with a waitlist of 3500 people applying for at home care funding (Cleek). And these are the individuals who have had enough support to make it through the application process. According to Shane Bear Heels, a quadriplegic man who has lived in a nursing home for over 12 years, it is functionally impossible to leave the care facility without an advocate from outside (Thomas, Fink, and Smith). Many of the Medicaid waivers for home-based care require people to have some form of outside support, which Hackney points out is "usually family, and if [disabled people] had that support, they wouldn't be in a nursing home in the first place" (Cleek). Additionally, after being institutionalized for so long, people are often completely isolated from the "normal" world —

they don't have a house or a job to go to if they were to leave, which makes the transition that much more difficult. It is also logistically difficult to work towards acquiring these things and/or a Medicaid waiver for at-home care while disabled people are being confined to living in a nursing home. Advocates can also be helpful to a disabled client to assist in managing care providers if they need it, a role that cannot always be fulfilled by a client's family or friends.

The home-care covered through Medicaid also has many restrictions that make it an unviable option for those who desire it, such as putting limits on how many hours aides can work and what times of day home aides will be covered by Medicaid funds (Thomas, Fink, and Smith). Furthermore, there is a lack of accessible housing options for those who desire at-home care, so even when disabled people have the care, there is no guarantee that there will be housing in their communities which will accommodate their disability and give them full mobility and access. Another part of what keeps disabled adults institutionalized is the lack of care services available outside of the nursing home setting (Pear). Even with Medicaid funding for home-based care, there is also a lack of care providers nationwide. This is felt particularly strongly in more rural areas, where there are fewer care providers and the likelihood that a provider lives reasonable close to those desiring their services is small (Thomas, Fink, and Smith). While home-based care is currently not a realistic option for everyone, a shift towards group living communities, where everyone has their own living space, privacy, and jurisdiction over their daily schedule would be a vast improvement over the current system of institutionalizing people in nursing homes.

Many states have been reluctant to let go of the idea of placing disabled adults in nursing homes instead of providing for home-based care options. This is even with the fact that covering

one person's home care cost for a year is half as expensive as paying for them to stay in a nursing home for that year (Cleek). It is appealing to those in power positions of the medical industrial complex to resist these changes. A shift towards home-based care would change the money flow — Medicaid dollars would go to companies which hire and manage care providers instead of through nursing homes and other institutionalized care facilities.

In face of the institutionalized powers which are keeping many disabled adults isolated in nursing homes, there are many advocates and organizations that fight for the rights of disabled people. There are people dedicated to helping people get out of care facilities and into home-based care programs. Advocacy organizations exist on a variety of scale levels. The National Disability Rights Networks serves as a resource to connect people with disabilities to legal resources. Because Medicaid rules vary by state, it is important to access resources and support from state-specific advocacy groups. There are other activist groups such as ADAPT, which calls for disabled people of all ages to be moved out of institutions and back into their communities. They are very involved with politics and have a program called Access Across America that aims to help disabled people transition from living in nursing homes and other institutions to living at home (“Housing”). ADAPT wants Access Across America to be implemented by the U.S. Department of Housing and Urban Development as a means to offer federal support for people seeking home or community based care where there currently is none.

Although this report has been U.S. centric, this is not an isolated problem. There are near identical trends in the institutionalization of disabled adults in Australia. There are over 6000 young disabled people in nursing homes in Australia, and they experience the same lack of agency and privacy as those in the United States (“Forced”). There are activist groups such as

The Summer Foundation which are working with politicians to provide avenues for young people with disabilities to return to their communities. The Foundation is advocating for more community-based group apartment complex options, where disabled people can live freely with total agency over their lives, while also having assistance available at any time should they need it. This may also be a viable option to decrease the number of disabled adults in care facilities for states in the United States which cannot support as many home-based care programs due to geographic conditions or a lack of caregivers.

The care options for people with disabilities who require assistance with daily tasks and who rely on Medicaid to cover their needs are disastrously limited. Even with legislation requiring states to offer home-based care options for Medicaid recipients nearing its 20th year of existence, in Alabama alone there are thousands of people waiting to get out of nursing homes, with under 20 people having done so as of 2013 (Cleek). Advocacy groups are still hard at work providing legal resources to institutionalized people to help bring forth lawsuits to get them the freedom to return to their own homes. Every person with a disability should be able to maintain agency and control over their lives, regardless of their reliance upon government funding to access care.



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