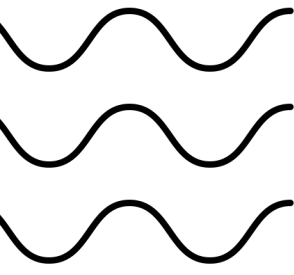
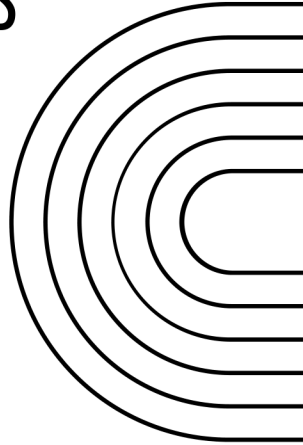




HUNGER FREE COMMUNITY REPORT
Bill Emerson National Hunger Fellowship



FOOD, FREEDOM, AND CHOICE: BALANCING NUTRITION AND INDEPENDENCE IN GROUP HOMES



Prepared by:
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In collaboration with:
The Massachusetts Developmental Disabilities Council,
The South Shore Community Action Council,
& The Congressional Hunger Center



MASSACHUSETTS DEVELOPMENTAL DISABILITIES COUNCIL



The MDDC is an independent agency, funded by the federal government, dedicated to empowering people with developmental disabilities and their families to enjoy full productive lives by promoting self-sufficiency, community inclusion & opportunity.

SOUTH SHORE COMMUNITY ACTION COUNCIL



We work to alleviate poverty, create opportunities, and increase the financial stability for low-income people so that every member of our communities - regardless of income - can live with dignity, reach their fullest potential, and enjoy all that is wonderful about life on the South Shore.

CONGRESSIONAL HUNGER CENTER



Founded in 1993 by a bipartisan group of Members of Congress, we are a global nonprofit organization dedicated to the principle that access to nutritious, affordable, and culturally appropriate food is a basic human right. We develop, inspire, and connect leaders in the movement to end hunger, and advocate for public policies that will create a food secure world.

AUTHOR'S NOTE

The disability community uses two main forms of referring to disability: person-first language and identity-first language. Some members of the community have a strong preference in favor of one form of language over another.[1] In an acknowledgement of both forms, in this report the terms are used interchangeably.[2]

When I started my research regarding group homes and adults with developmental disabilities, I was shocked at the lack of information available. Nutrition is consistently seen as a secondary expense. Unlike other nonnegotiable expenses – rent, utilities, transportation – nutrition can be minimized. Because of this lack of freedom for those of a low socioeconomic status, nutrition is often put on the backburner. Not necessarily because one wants to, but because one must.

This became clear in my interviews with the Department of Developmental Services and an array of residential facilities for adults with I/DD. There is no mandated cooking class for support staff, no mandatory training on how to balance personal preferences and healthy choices, no mandatory dietician or nutritionist who oversees group homes; there is simply Executive Order 509, an order from over a decade ago that was intended for larger institutions.

Furthermore, the Massachusetts Department of Health (DPH) produced the State Agency Food Standards document from EO509, which reflects the dietary recommendations from the U.S. Department of Agriculture (USDA) is from 2005-2010. This document outlines what one can and cannot eat and has not been updated since 2012.

When one's health and well-being is put into the hands of others, it is necessary that we are extremely cautious in our practices so that we maintain consistent and beneficial results. After interviewing group homes, state agencies, and other community stakeholders, this report summarizes my findings. It should be noted that most of these results are subjective as they were formulated through a variety of interviews. Consequently, the work is written through a lens of equal opportunity and the fundamental human right of freedom of choice.

In many conversations, it was clear that the intention to help adults with developmental disabilities by giving nutritional guidelines to staff was not consistently resulting in an outcome that centered the disabled person or allowed the disabled person to be a part of those choices in any capacity. In a setting where many decisions are structured, it is vital that residential services prioritize independence whenever possible, especially regarding health and nutrition.

It is important to note that the subject of this report outlines the potential and practical misinterpretations of the State Agency Food Standards and other social or political nutritional “standards.” There are residential services that fully understand the unnecessary restrictions imbedded in the State Agency Food Standards document and that aim to create culturally appropriate, nutritious foods within group homes. There are residential services whose support staff are excellent chefs, and actively prioritize the preferences and opinions of disabled people in making meal plans and menus. However, the fact that this is not the case for all group homes along the south shore is inherently problematic.

As outlined below, policy changes must occur for these practices to be consistent. When we patronize adults with developmental disabilities by thinking that we know better than they do about their own health and well-being, we begin to dehumanize them. The entire residential disability service system has the potential to create a cycle of poverty, consisting of restriction and dependence. By constituting these policies and practices, we make people with disabilities dependent on us for all of their needs, with no mandate to consider their wants or personal preferences; with no mandate to humanize them.



DEVELOPMENTAL DISABILITIES AND RESIDENTIAL SERVICES

TERMINOLOGY ABOUT I/DD

In this report, I will be using language recommended and most frequently found by the I/DD community. Verbiage such as “disabled people” and “people with disabilities” are used to refer to adults with intellectual/developmental disabilities. In the disability space, there generally exists two main ways of referring to disabilities: person-first language (PFL) and identity-first language (IFL).[3]

PFL is intended to emphasize the person before their disability. Terminology such as “person with a disability” or “person who uses a wheelchair” are examples of this kind of language. Generally, one should default to PFL when referring to someone with a disability, unless they have stated their preference otherwise. In other words, one’s disability may be a characteristic of their identity, but they prefer not to be defined by it.

IFL is intended to acknowledge one’s identity as an integral part of who they are. Verbiage such as “disabled person” or “Autistic person” are examples of IFL. In this case, identity-first language connects a disabled person to a larger community and history. Many disabled people have strong preferences for PFL or IFL, so for the purposes of this report I will be utilizing both ways of referring to disabilities.

Especially due to the nature of this report regarding the increase in independence of disabled people in group homes and reimagining the normalcy of choice in community-living spaces, it is important to continue utilizing this terminology in reference to persons with I/DD. A broad definition of Intellectual/Developmental Disabilities is as follows:[4]

IDDs are differences that are usually present at birth and that uniquely affect the trajectory of the individual's physical, intellectual, and/or emotional development. Many of these conditions affect multiple body parts or systems. The term "developmental disabilities" is a broader category of often lifelong challenges that can be intellectual, physical, or both.

Intellectual disability starts any time before a child turns 18 and is characterized by differences with both:

- Intellectual functioning or intelligence, which include the ability to learn, reason, problem solve, and other skills; and
- Adaptive behavior, which includes everyday social and life skills.

GROUP HOME BACKGROUND

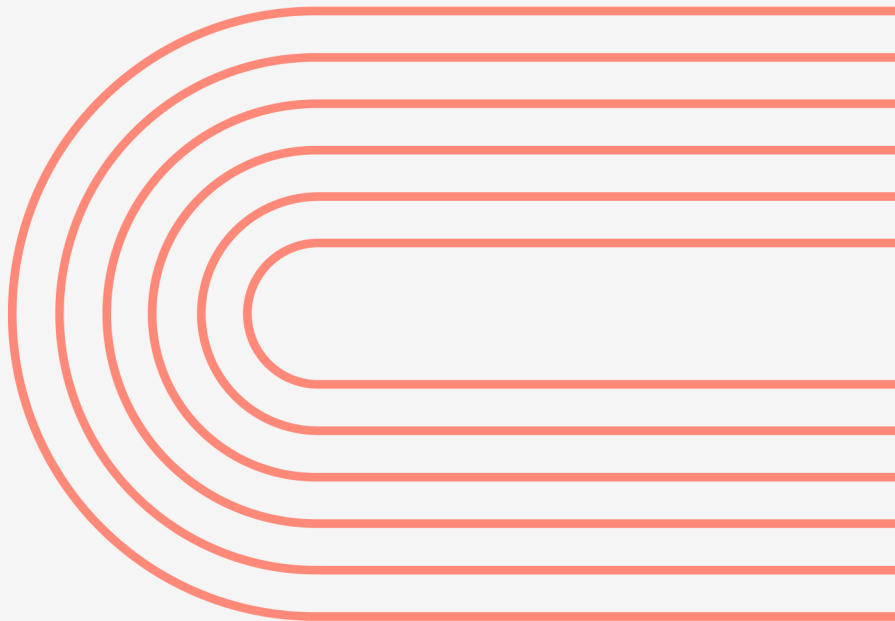
When adults with developmental disabilities turn 22 years old, they transition from the special education system to the adult service system.[5] During this transition, many developmentally disabled adults apply for services with the Department of Developmental Services (DDS). Once they are found eligible for services, the disabled person is paired with a DDS area office. [6] It is here that residential determinations are evaluated and recommended in consultation with the person's family and provider agency.[7] The different types of provider care options are as follows: [8]

COMPARING MODELS OF RESIDENTIAL SERVICES

	Residential	Shared Living	Individual Supports	Self-Direction
Amount of time supervised	24-hour supports	Frequent and consistent support	Minimal time supervised; varies by individual	Minimal time supervised
Level of support	Intensive support for individuals with significant health/safety needs	Constant, but less intensive support	Intermittent assistance to maintain independent-living situation	Varies by individual's self-direction plan
Type of Support	Supported by staff at a DDS-regulated provider agency	Supported by host family trained by agency	Supported by staff at a DDS-regulated provider agency	Staff selected or hired by individual or their family/guardian
Location	Group home	Host family's home	Independent living situation (home or apartment)	Independent living situation or family home

<https://www.mass.gov/doc/transition-information-fact-sheets-english/download>

The goal of all residential care settings is to “ensure the health and safety of residents,” while also “striving to promote the utmost independence and personal growth.”[9] The type of residential service that serves people who need the “most intensive level of support” is 24/7 care, or group homes.[10] The state of Massachusetts has approximately 2,200 group homes.[11] Group homes are community-based housing where a small group of people with disabilities live together while receiving support from nurses and day and night support staff. This type of group home and its staff are the focus of this report. In any congregate care setting where services are being provided 24 hours a day[12] there is a natural tension between providing support and promoting decision-making and independence. And in such a highly regulated setting, policies can at times result in restricting independence rather than promoting it, particularly when policies are not tailored to these unique settings.



MEDICALIZATION OF I/DD

PEOPLE WITH DEVELOPMENTAL DISABILITIES ARE MEDICALIZED

Adults with developmental disabilities are constantly “othered” by society. They are perceived as “abnormal” and need help to function “correctly” according to our social standards by way of professionalism or personability. In fact, we aim to see those with I/DD as so integrated into society that we don’t notice the disability at all. Inherently, this type of mindset behind integration is problematic and lends itself to the medicalization of those with developmental disabilities.

Disability advocate Emily Ladau writes that the medical model perpetuates the negative attitude towards disability as a problem that needs to be fixed.[13] However, it must be noted that the medicalization of developmental disabilities to some extent does benefit the community in bringing awareness and transparency to the difficulties and barriers that the I/DD community faces – medical or otherwise. In this sense, the issue becomes this: through the process of medicalizing I/DD, we have overcorrected for enhancing support by maintaining control. Institutions such as group homes and other types of residential care, although intended to give disabled people independence while creating a space for support, if they so choose, can become problematic. Receiving medical aid, or being at a higher risk of obesity, heart disease, or other health issues require support, not control.

For example, residential settings and their staff can take on a savior complex regarding disabled people. They may be so blinded by what they deem is “normal” or “functioning” behavior that they overlook the aim of residential settings: providing choice through informing.

By making decisions for people with developmental disabilities, they are – perhaps unintentionally – undermining the goal of these group homes: creating a transitional space for residents to have increased support and community prior to independent living. It should be clear, then, that by taking away choices – although well-intended – they are ultimately restricting freedom of those who are developmentally disabled.

Seeing a disability as “problem” that needs to be fixed using the medical model continually others those with I/DD. Although there is merit to this model by recognizing the relevancy of a disability to the lives of those with I/DD, it also ignores the fact that the effects disability extend past just a person's body.[14] The medical model also perpetuates stereotypes regarding the intellectual capacities of people with disabilities such as falsified ideas regarding “mental age” and inability to make decisions regarding one’s own body, health, and well-being. These ideas, unfortunately and often unintentionally, can bleed into the mentality of staff at group homes and the greater residential providers.

SOCIAL AND POLITICAL INFLUENCE OF NUTRITION AND FOOD CHOICE

In addition, these institutional players are also socially and politically influenced as to what should be deemed “healthy” and “unhealthy”. However, these influences can negatively impact the choices they make for disabled people that may conflict with their own personal wants, needs, and doctors’ recommendations. Common misconceptions about the dangers of carbohydrates or sugars, fad diets, and beauty standards of popular media can all contribute to a personal mindset of what people should and should not eat.

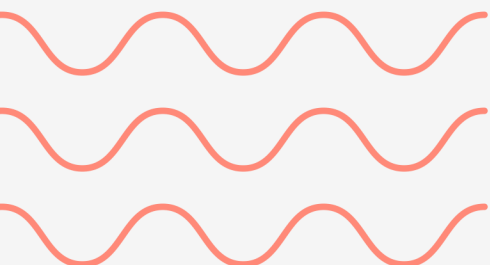
However, it must also be noted that staff at residential institutions are also influenced by the mandating of Executive Order 509, and its subsequent State Agency Food Standards document. This order includes nutritional recommendations from the Department of Public Health and is given to the Department of Developmental Services (DDS) who must enforce these policies at residential homes. Although informing disabled people about what health substitutions and recommendations for a household can be beneficial, non-consensually enforcing these standards to a residential service is a violation of human rights.

Arguably, even more problematic is the paternalistic stance these social and political influences can take. The idea that staff, who are often not trained in cooking or nutrition, believe that they know what is best for an individual is not only inherently condescending, but it also perpetuates a problematic narrative that developmentally disabled adults are child-like. Archaic notions of mental age and stereotypes of treating adults with I/DD as children are further reinforced when limiting food choice and restricting freedom.

IV. COUNTER-PRODUCTIVE POVERTY POLICIES THAT INHIBIT INDEPENDENT LIVING

RESTRICTION OF FEDERALLY FUNDED FOOD PROGRAMS (SNAP, WIC, ETC.) IN GROUP HOMES

The intent of federally funded, social safety nets such as the Supplemental Nutrition Program (SNAP) and Women, Infants, and Children (WIC) is to temporarily aid in financial loss for people and families who are living at or around a poverty-level income. These programs are also designed to allow for independence and choice of foods, albeit with caveats, for those of a low socioeconomic status. However, in residential settings for adults with developmental disabilities, these financial safety nets are taken from individuals and pooled into the total group home grocery budget. Not only does this defeat the purpose of these programs being social safety nets - allowing adults with I/DD to financially supplement their expenses -- it also strips disabled people of choice as a human right. It bears repeating that this may not be the exact case for all group homes, but the influence of these policies in any group homes can create a dangerous precedent. The restriction of choice, the stripping away of SNAP or WIC benefits, is harmful to the prospect of disabled people transitioning to independent living as it creates a false narrative of how much one can spend on food, what they can purchase with these federally funded programs, and what healthy choices and moderation can look like.



In addition to the restriction of the Agency Food Standards document, in many cases group home residents who qualify for SNAP (Supplemental Nutrition Assistance Program) assistance are unable to access their own SNAP benefits. Instead, SNAP benefits are pooled for the entire household, and then allocated to the house's grocery budget – ultimately increasing the per-person food budget. The SNAP program is intended to be a supplementary social safety net for individuals with a low-socioeconomic status; the program is not intended to supplement per-person food budgets in group homes. Staff at many group homes who do grocery shopping must shop at certain traditional grocery stores due to an ongoing account held by the store intended for group home use. These traditional grocery stores do not participate in HIP(Healthy Incentive Program).

When residents are unable to utilize their own SNAP benefits, they are also unable to participate in HIP. Massachusetts HIP is intended to incentivize adults to utilize their SNAP benefits at local vendors to buy healthy fruits and vegetables; this is done by putting money back on one's EBT cards when they purchase healthy foods at these local vendors. HIP is intended to support individuals in buying healthy fresh foods, as well as local vendors who produce and sell these foods. However, when SNAP benefits are conglomerated into an entire household budget, these incentives do not exist.

It is my understanding that residents in group homes are further restricted in what they can and cannot purchase and eat. Because the residents' SNAP benefits are given to the residential settings, they then fall under the purchasing restrictions of the Agency Food Standards. They have become property of the residential setting, and the discretion of the residents is lost.

GOALS AND POLICY RECOMMENDATIONS

POLICY RECCOMENDATION #1:

REVISION OF STATE AGENCY FOOD STANDARDS DOCUMENT BY THE MASS DEPARTMENT OF HEALTH

This revision should include:

Updated nutritional information from 2020-2025

The current State Agency Food Standards document does not account for the advances in technology, science, and medicine in the last 15-20 years. Executive Order 509 calls for the creation of food recommendations and restrictions for all state agencies. However, the current document that is used is based upon the dietary guidelines for Americans from 2005-2010, a document that is updated every 5 years. Consequently, the information included in the State Agency Food Standards document does not encapsulate what the USDA currently deems as healthy. For example, nutritional labels were changed in 2020, and the document does not have an example of the revised food nutritional label, although it alludes to how one should read a food label.[15] Additionally, the use of artificial trans-fats was deemed unsafe by the FDA and is no longer allowed in foods produced and sold after January 2020.[16]

This allows for group homes and adults with developmental disabilities to not only have more flexibility in grocery shopping considering newfound options, but also shows that nutrition and food choice should be prioritized in a setting where adults may have sensitive medical issues that call for greater care and attention to food options (heart disease, kidney problems, etc.)

Include a values statement for independence and choice

This would acknowledge that adults with developmental disabilities can make decisions for their own health and well-being, and although support and guidance through staff training and this document should be used as a form of guidance, understanding one's body – hunger cues, cravings, etc. – should also be prioritized. Independence and choice over one's body is a fundamental human right, and adults with developmental disabilities are not an exception.

Making choices for adults with developmental disabilities is, inherently, a condescending form of paternalism. Not only does it perpetuate the white-savior complex, it also perpetuates the stereotypes of disabled people as children such as their “mental age” being younger than their biological age, that they should not be able to procreate, or that they cannot or should not participate to sexual activities.

Ideally, if a disabled person wants to move from a staff-supported living facility to independent living, it is essential that they understand for themselves what food items they should or shouldn't eat in accordance with their preferences and medical restrictions. The idea that adults with developmental disabilities could not make these choices for themselves is inherently ableist. However, in order to make choices, one must be presented with options. When people with I/DD are stripped of these options, they are left with no choice at all.

POLICY RECCOMENDATION #2:

ALLOW RESIDENTS TO USE THEIR PERSONAL SNAP BENEFITS

In group home settings, residents who qualify for SNAP assistance are unable to access their own SNAP benefits. Instead, SNAP benefits are pooled for the entire household, and then allocated to the house's grocery budget - ultimately increasing the per-person food budget. However, when residents are unable to utilize their own SNAP benefits, they are also unable to participate in HIP (Healthy Incentive Program). Massachusetts HIP is intended to incentivize adults to utilize their SNAP benefits at local vendors to buy healthy fruits and vegetables; this is done by putting money back on one's EBT cards when they purchase healthy foods at these local vendors. An example from the Massachusetts Department of Transitional Assistance (DTA) is copied here: [17]

You have \$50 in your SNAP balance. A HIP vendor charges you \$10 in SNAP for tomatoes and strawberries. The \$10 you spend in SNAP is instantly replaced on your EBT card. Your receipt will show that your SNAP balance is still \$50 and that you have used \$10 of HIP toward your monthly cap.

This program is intended to support individuals in buying healthy fresh foods, as well as local vendors who produce and sell these foods. However, when SNAP benefits are conglomerated into an entire household budget, these incentives do not exist.

Additionally, the SNAP program is intended to be a supplementary social safety net for individuals with a low-socioeconomic status; the program is not intended to supplement per-person food budgets in group homes because the state budget is too little to create a healthy lifestyle.

Staff at group homes who do grocery shopping also are mandated to shop at certain traditional grocery stores due to an ongoing account held by the store intended for group home use. These traditional grocery stores do not participate in HIP.[18]

When residents can use their own SNAP benefits to purchase local healthy foods, they are also aiding in the larger food systems cycle by helping local farmers and food vendors. If the per-person food budget for group homes is too little to create healthy eating, then a conversation regarding an increase in state-funds should be in question - not taking away the social safety nets afforded to disabled individuals of a low socioeconomic status.

FURTHER RECOMMENDED RESEARCH

The following policies and practices inhibit independent living for disabled people who currently live in group homes. These restrictions frequently appeared during my environmental scan, and should also be addressed when emphasizing choice and freedom in these settings.

THE "SPEND DOWN" AND ENFORCED POVERTY

One counter-productive poverty policy is what residential services have coined a "spend down." This process of limiting people with developmental disabilities' personal finances not only limits their ability to transition out of residential services to independent living, but also embeds the notion that disabled people are not capable of making financial decisions and should not be financially independent.

When disabled people join group homes, they must pay a "service fee," which, generally, is 75% of their SSI (social security income). In majority of cases, the other 25% of their SSI must be managed by a rep payee. If the disabled person does not have someone who is willing to be their rep payee, they must pay monthly for this service. After the rep payee uses the remaining SSI to pay for their other bills, the surplus can be used for personal reasons. However, if the person with a developmental disability is working over a certain amount of hours per week, because their SSI decreases as employment increases, the Department of Disability Services takes 50% of their paycheck to accommodate for the loss in service fee. Even if the disabled person is not employed to an organization related to the residential service this process still occurs. Thus, enforced poverty begins.[19]

The incentive for people with disabilities to be integrated into the workforce is little to none, as they would only be compensated for half of their employment. In addition to this exploitive labor, adults in residential services face a “spend down” in which they are required to have below the threshold of \$2,000 per month in their savings accounts to keep their Social Security Income. In this way, disabled people are unable to transition to any type of independent living following their time in group homes, as they would not have the financial capacity to support themselves under this “spend down” process. In addition to creating and maintaining cycles of poverty by putting a cap on personal finances, this process also enforces the mentality that adults with developmental disabilities need to be controlled and are not capable enough to make independent decisions that impact their health and well-being.

POTENTIAL POLICY RECOMMENDATION: ELIMINATE SPEND DOWN AND REVISE CAP ON SAVINGS

For adults with developmental disabilities to transition from group housing to independent living – if they so choose – they must prepare financially. It would be virtually impossible for any person to finance their own housing without saving for rent, a security deposit, utilities, in addition to food, furniture, comfort, etc. For example, the average monthly cost of rent alone in Plymouth County, MA is \$2,663 -- \$633 more than the cap on saving for disabled people living in group home settings.[20] In this sense, if a person with a developmental disability aimed to transition to independent living from a group home, they would no longer qualify for their social security income – the income that currently pays for the group home – and they would have to be completely financially independent, which, given how difficult it is for disabled people to be hired, would be extremely difficult.

In this sense, keeping disabled people dependent on group homes to maintain their social security income is a type of enforced poverty. In addition, residential services taking 50% of employment benefits due to the decrease in social security income is, in fact, an exploitation of labor.

This lack of upward mobility and cyclical poverty perpetuates the stereotype that disabled people should be isolated from society, and are not capable of living independently when, in fact, these policies don't allow for a transition to independent living and create this barrier. In essence - disabled people are forced to choose between independence, and financial support. They cannot have both.



I/DD IN THE BIPOC (BLACK, INDIGENOUS, PEOPLE OF COLOR) COMMUNITY

Because developmental disabilities can often arise from genetics or prenatal issues,[21] it is clear how factors such as environmental racism, increased levels of depression and anxiety, or high maternal mortality rate within the BIPOC community can correlate to an increased likelihood of children with developmental disabilities.

In my environmental scan, I found little to no public information regarding the intersection between disabled BIPOC and food insecurity. Although there appears to be research on the experiences of the broader disabled BIPOC community, hunger in the disability space, and hunger in the BIPOC space, specifying the experiences of those with intellectual/developmental disabilities proves an existing gap of knowledge. This was a barrier in my project, and further discussion and research is needed to provide insight into the intersection of hunger, BIPOC, and I/DD. Recent developments at the Massachusetts Developmental Disabilities Council regarding developmentally disabled BIPOC further proves that this community does exist but is gravely overlooked and under-researched.

As such, it is pertinent that the Department of Health and the Department of Developmental Disabilities put the lived experiences of disabled BIPOC at the forefront of all conversations. Understanding that disabled BIPOC are disproportionately affected by hunger and health disparities is necessary for racial equality.



CONCLUSION

The developmental disability community is often unseen. An inability to attain work, a tradeoff between social security income and financial independence, and extreme social stigma all work to suppress the dignity and freedom of adults with disabilities in the United States.

It is important to note the nuance imbedded in the notion that disabled people choose to live in group home settings for their entire life. When one is never exposed to other options, such as independent living or shared-living arrangements, they can become institutionalized into believing that the restriction that goes along with group home settings is okay, or tolerable. Knowing that an option that allows for more independence exists is, perhaps, half the battle.

For disabled people, asking for support or guidance should not necessitate restriction. One should be able to live comfortably and freely in their own home, and the idea that society must maintain control and power over seemingly vulnerable individuals is internalized paternalism; a savior complex that maintains the status quo. These policies perpetuate harmful notions of developmentally disabled adults as children -- “mental age” in reference to intellectual capacity, disabled adults should not procreate, or participate in sexual activity.

By recognizing these shortcomings and eliminating these requirements, we are ultimately empowering a class of individuals who are often limited in freedom by the healthcare system, the social safety net, and larger society. To make decisions one must have choices, and it is our personal liberty and freedom to make them for ourselves.

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