

Bureaucratic Efficiency Versus Independent Living Philosophy

by Charlie Carr

7 reasons why the MassHealth IAE proposal clashes with independent living philosophy and will result in a failed outcome for ILC Personal Care Management (PCM) agencies

Background and context: Overall, the philosophy of independent living emphasizes empowerment, choice, and community inclusion for individuals with disabilities. It is a rejection of the medical model and exemplifies consumer control, choice and the dignity of risk.¹ A centralized nursing agency for eligibility decisions done by nurses that have no background in independent living most likely will not align with these principles and could impede progress toward achieving true independence and inclusion. While centralized systems may offer administrative efficiency, they risk overlooking the nuanced needs and rights of individuals with disabilities. Independent living advocates have consistently fought for decades,² for more inclusive and participatory approaches that involve people with disabilities, to ensure fair and equitable access to PCA services in order to live independently outside of an institution.

1. **Lack of Representation:** A single Independent Assessment Agency (IAE) most likely will not adequately represent the diverse needs and experiences of people with disabilities across the state. Different types of disabilities require different types and levels of personal care, and a one-size-fits-all approach does not address these variations. Time to Task (TTT is one of several examples). The time it takes a PCA to brush the teeth of a person with spastic athetoid Cerebral Palsy generally takes longer than somebody with a Spinal Cord Injury and doesn't fit within the allotted time given for that function. Personal Care Management (PCM) agency nurse evaluators whether they are contracted or on staff, understand these individual differences and embrace the independent living philosophy. It is a requirement as a result of onboarding training and working in an ILC controlled by disabled people.
2. **Limited Understanding:** Nurses may not always have a comprehensive understanding of the daily physical requirements and needs faced by individuals

¹ <https://www.independentliving.org/docs5/Osterwitz.html>

² https://www.ilru.org/sites/default/files/History_of_Independent_Living.pdf

with disabilities. This lack of understanding most likely will result in eligibility criteria decisions that are too restrictive or fail to capture the full scope of assistance required. This is painfully underscored by trying to effectively apply a single set of eligibility criteria to over 400 agencies with very different disability populations and living arrangements.

3. **Potential Bias:** Depending solely on a single entity to determine eligibility most likely will lead to biases or subjective judgments that disadvantage individuals with disabilities especially those from marginalized disability groups and who live in inner city/rural poverty areas. Independent living values community involvement and peer support. A centralized agency can't and probably won't adequately involve local communities and disability advocacy organizations in decision-making processes, leading to decisions that are out of touch with the lived experiences and needs of individuals with disabilities.
4. **Risk of Bureaucracy and Delay:** A centralized agencies may introduce bureaucratic processes and delays in accessing services, hindering the timely provision of support needed for independent living. This can create barriers to full participation in society for individuals with disabilities as required by law.³
5. **Reduced Flexibility:** A centralized system may lack the flexibility needed to accommodate changes in an individual's condition or circumstances over sporadic periods of time. This could result in delays or difficulties in accessing essential care and support services.
6. **Loss of Autonomy:** Placing eligibility determination solely in the hands of a single entity diminishes the autonomy of people with disabilities to advocate for their own needs and preferences in accessing personal care assistance services. Independent living philosophy emphasizes self-determination, control and autonomy for individuals with disabilities. Relying on a centralized agency to make eligibility decisions jeopardizes the ability of individuals to control their lives. This philosophy is the backbone of the PCA program.
7. **Potential for Institutionalization:** Centralized systems can sometimes lead to institutionalization or segregated care settings, which go against the principle of independent living that promotes integration and inclusion of people with disabilities into mainstream society.

³ <https://www.hhs.gov/civil-rights/for-individuals/special-topics/community-living-and-olmstead/index.html>