

# Disability Community Promise

A policy proposal towards disability justice by David Zoltan

Illinois has taken a passive approach to getting disabled people into community despite the promise made to us in the Americans with Disabilities Act back in 1990. Thirty-two years later, far too many disabled people still are forced to live in nursing facilities, group homes, Community Integrated Living Arrangements (CILAs), and other institutional settings. This passive approach relies on these institutions that make money for their owners and/or upper management by stockpiling bodies and collecting the money, largely from Medicaid or other federal programs, to help their residents move out. That is clearly not in their best interests, and as a result, many of those disabled folks remain trapped in these facilities against their will or even, at times, not knowing there is even another option.

Even the best current program out there for getting disabled people into community, the Money Follows the Person (MFP) program under Medicaid, is poorly implemented and greatly lags behind most other states that have been involved. This program was created at the federal level to help disabled folks achieve this promise as well as being a recognition that disabled people living in community costs a third of leaving them in institutions. Meanwhile, Illinois is one of only seven states that does not have an active state administrator registered with the Centers for Medicare and Medicaid Services, and the website concerning these programs is so old and out of date that it references people being appointed to the disability advisory board by Gov. Blagojevich. Clear signs that Illinois has fallen down on utilizing this important program that offers funding to help get disabled folks into community.

The program that actually houses the use of these funds under IDHS, the Active Community Care Transitions program, has red flags all over the pages discussing the program. First, it gives no agency to the disabled person directly and assumes that family or guardians are in control rather than the person themselves. Second, it presumes that the disabled person should be moved from a nursing facility to a group home, a mere shuffling of institutional settings, rather than actually independent living in community with HCBS delivered directly in the individual home. Third, it interchangeably refers to the "individual" having control with the "family", clearly showing the contempt for actual agency by the disabled person in question. The problems sprawl out further from there.

Additionally, Illinois falls under several consent decrees, judicial oversight meant to force governments to follow decisions made against them, that stem from the Olmstead Supreme Court Decision. The Colbert Consent Decree covers so-called "skilled" institutions and continues to fail to meet reasonable compliance with that decree. Given that an outsized proportion of deaths in the pandemic have occurred in institutionalized settings both nationally and here in Illinois, it is good that there has been a slight uptick in compliance in the past year. Yet, the state is still at only 37% full compliance with the decree over the 81 measurable requirements and 41% completely out of compliance. On the key factors of outreach, assessment, and service plan requirements that would lead to more institutionalized disabled people being educated on their options and given a real chance for community living, we are compliant on only 4 measurable requirements out of 42 and fully out of compliance on 26 factors. To say that the small uptick in compliance is too little too late would be a massive understatement, especially to the lives that could have been saved if the decree had seen swifter implementation prior to the pandemic even being a significant threat. The Williams Consent Decree covers psychiatric institutions, and we are similarly out of compliance with that decree. We have had somewhat better success with the Ligas Consent Decree covering state-run institutions, but improvements in efficacy are still easily possible there as well.

In the end, the failures of the current system are, in fact, cutting our nose to spite our face. Implemented properly, placing a disabled person in true independent living in community and surrounding them with supports and services there would save the state's Medicaid program approximately two-thirds of the cost of leaving them in an institution, to say nothing of the tremendous dignity given to the disabled person in question. That is money that could be better utilized to improve the lives of disabled people across Illinois.

The parallels to the cost savings realized by such a program to the savings realized by the state with a Housing First program should not be surprising. Taking the more proactive approach of Housing First and ensuring teams have access to institutionalized residents in scenarios that prevent coercion and can swiftly move resources to get those disabled people accessible housing in a community of their choice while surrounding them with the Home and Community Based Services (HCBS) they need without retaliation from the institutions involved would help Illinois to finally come right by disabled people in a big way. The success and efficacy of the Housing First approach has been proven by cities like Rockford, IL and others like it around the world which have, within just a few short years, effectively ended chronic homelessness.

Meanwhile, despite the great need for HCBS to ensure disabled folks can stay in community and get the care they need to do so, we must recognize that at the national level the Build Back Better Act was whittled down to the Inflation Reduction Act and that it ultimately passed without the HCBS promised in the original bill. It is now, for all intents and purposes, incumbent on the states to pass and practice these needed supports in the interim.

There is a major gap, on the scale of two to three times, between what home-care providers are being paid by Medicaid and what they are paid on the general market, to say nothing of the danger of putting a worker barely making minimum wage into situations where they are generally engaged in some of the most personal and intimate care in a person's home that they can be in. It not only causes a major deficit in the job market for home-care workers for those receiving benefits, but it encourages theft and other forms of desperate behavior from workers, as well as taking them away from their own families and disrupting any possible work-life balance in the process to make ends meet. With the current housing wage at \$26/hour in the state of Illinois according to the National Low Income Housing Coalition and a living wage around the same figure, it is imperative that workers get a sharp raise in pay and benefits paid through Medicaid and the cost savings realized via shifting to a Housing First methodology.

As such, the Disability Community Promise policy will seek to:

- Dissolve the current ACCT program and stand up a new program with a new mandate that centers the agency of living decisions with the disabled individual in question over any other, including using the most updated assistive communications strategies within the disabled community to ensure that every person is given that agency regardless of their verbal capacity.
- Adopt a Housing First methodology to placing disabled people in community from institutionalized settings. This program should utilize MFP funds as well as create any additional programs, vouchers, and subsidies needed to move every person that wants to live independently in community out of nursing facilities and group homes as soon as possible.
- Ensure that the individual is able to do a "walk-through" of the apartment chosen to be certain that it meets the needs of the individual and that there are no hidden difficulties prior to their move-in as well as assess where modifications may be necessary.
- Create a direct agency link to state Home Modification Programs that will allow for funds to be devoted to preparing the new home in community for any accessibility needs of the individual. Funds will be designated specifically for this purpose.
- Mandate that the governor appoint a grantee for the state to manage the Money Follows the Person program and ensure best availability of this federal funding source that already exists from CMS,

interface with appropriate agencies and individuals to ensure that currently institutionalized people are being placed in individualized homes in community and surrounded with the best HCBS services possible without undue influence of other parties including but not limited to family, nursing facility staff, or others; acting as both an administrative body and in an oversight capacity; while providing accountability to the Illinois Legislature moving forward.

- Connect implementation plans and coordination of MFP funding, Colbert line item funding, and other necessary programs under this new agency with a singular Housing First methodology and with a mandate to ensure the agency of the disabled people themselves.
- Add agency staff to certify disabled people far more quickly for HCBS services. No disabled person should wait more than a week to be certified for HCBS services so that they can move into community with all due haste.
- Set up accountability practices and reporting that will keep the Legislature informed of progress and success of the new program moving forward while also ensuring that problems and setbacks are brought forward and given a chance to be addressed as quickly as possible through additional legislation and program reforms.
- Increase the pay rate for home-care workers under the state's Medicaid, paid for through the cost savings achieved through this program given the suspected drastic drop, estimated at 66% savings to Medicaid, in cost of services to nursing facilities, CILAs, and group homes. This is also an opportunity to expand training opportunities and ongoing education requirements as well as demand higher accountability for these critical jobs.
- Establish these housing and supportive services as a right for all people with disabilities so that a robust HCBS program is available to all that need it without qualification.
- Streamline as much of the regulation as possible while ensuring best outcomes with the goal of moving disabled people quickly out of institutionalized settings without an abrogation of their rights to safe, affordable, accessible housing.
- Create stronger mandates on construction to ensure that all housing is accessible everywhere as the primary public need in housing construction is affordable accessible housing. All housing must be brought to standards where it is accessible, as participating in community is not just a matter of living in accessible housing but also being able to go to housing of others. Any inaccessible structure is an abrogation of that civil right. In addition, it should become a watchword of public policy that aging in place in our communities of choice be one of the highest of priorities in decision-making, both for the dignity of our citizens as well as for the drastic cost-savings to the state in the long-term. After 32 years, it is time to start moving towards ending the grandfathering of older buildings to ensure these principles.
- Empower the current panels and councils on disability to submit enforceable accessibility features that address any disabilities that are not addressed in current federal standards to be made part of an accessibility mandate for the state. A review of what panels and councils currently exist for disabled people in the state should be conducted and any consolidation and filling out of those panels and councils should be implemented post-haste. Accountability for the executive branch to address and communicate with these panels and councils and use them for actual policymaking rather than having them serve only for appearances should be incorporated as well to discourage ableist wasting of time and energy. Serving on a panel or council should be compensated as important labor on behalf of the people.
- Respite is where a disabled person in community is placed back in institutional care on a supposedly temporary basis. In practice, this has not been how respite has worked, however, and has trapped many people back into institutionalization. Wherever respite is recommended, it must occur only with the clear and express authorization and consent of the disabled individual, must come with a concrete and written plan to get the disabled person back into their home in community on an expedited basis, and must allow for the agency of the disabled person to end the respite period at any time for any reason and have their care resume in their home in community instead.

# Disability Justice Platform - Spring Session 2023

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## Disability Community Promise

Implement Housing First to actively move disabled people out of institutions and strengthen Home and Community Based Services pay and practice for those in community.

## Housing First Expansion

With over 60% of unhoused people being disabled, it is essential to connect state housing funding to mass implementation of Housing First to solve chronic homelessness and save the state tremendous money.

## Medicare for Illinois

Disability justice is impossible without a healthcare system that works for the people, is cost-effective, and ensures human rights and dignity.

## Affirmative Disability Accommodations for Workers

Removing ableist barriers to working must be a priority, to help those currently in the workplace as well as enable those that are left out of the workplace to enter the labor force.

## Equity in Transit Access

Access to transportation remains a travesty in Illinois, and critical human rights stipulations and investments must be made to make it equitable for all disabled people across the state.

## Social Housing Acquisition Fund

Corporations are buying up housing at a rapid pace, even as we struggle to keep and create affordable accessible housing. This fund would enable tenants to have first right of refusal on their housing when it's being sold, ensure that that housing is permanently affordable, and place democratic control of that housing in the hands of the tenants.

## Removing Barriers to Housing

While Source of Income Protection is now Illinois law, credit checks, eviction history, incarceration history, and housing restrictions based on convictions remain as major barriers, especially to disabled folks.

## Homes are for Housing

While we can't simply build our way out of the housing crisis, homesharing services abused by landlords taking units, including but not limited to accessible units, exacerbate the problem and must be regulated.