

# POLICY STATEMENT

## How Money Follows the Person (MFP) Helps Support Independent Living

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### My Story

I am a 43-year-old woman who has Cerebral Palsy. For most of my life, I've used a wheelchair and other assistive devices to get around and do the things I love and need to do. I feel very lucky to have grown up in a family who encouraged me to be whoever or whatever I wanted to be. I am also very lucky to live in my own home in my community, with Home-and-Community-Based Services (HCBS). HCBS are services which provide assistance with daily activities that generally helps the elderly and adults with disabilities remain in their homes. One such service I receive is Personal Care Services (PCS), which allows me to have caregivers from a local care and hospice agency in my home on a daily basis. Skilled nursing or certified nursing assistants help me with housekeeping, cooking, shopping and personal care needs. Without these services I would be living in an intermediate care facility for people with developmental disabilities (ICF/DDs)--a smaller community-based facility where 6-16 people live together not by choice, as I require a high level of care. Through PCS, however, I have more independence than I thought possible. I'm an active, productive member of my community. In addition, I've been active in disability advocacy for 15 years, and I've been able to pay it forward by helping to improve the quality of life for people and families of children with disabilities.

### A Brief History of Institutions and Self-Advocacy

Unfortunately not everyone with disabilities, adults or children, have been as lucky as me. Due to varying circumstances, such as a family being unable to provide suitable care, many people with disabilities have been institutionalized. As residents in institutions, they lack a great deal of independence: the freedom to go where they want, the right to choose which activity they want to do and who they want to be friends with. Sometimes they are not even allowed to see family members. Their amount of dignity as human beings is lessened. In some facilities, residents are not allowed to have doors to their bedrooms and are treated like children. Many people living in these facilities feel separated from their communities. In 1967, the move towards helping people with ID/DD live with the right supports in their communities began, but many large state-run institutions are still open across the United States.



Institutions are typically thought of as large hospital-like buildings run by the states. The federal government also considers ICF/DDs institutions. State-run institutions are often built in rural areas for safety reasons.

In 1995, two women living in institutions in Georgia sued the state, saying isolating people with disabilities was against the Americans with Disabilities Act (ADA), instead of receiving treatment in their own community. The United States Supreme Court agreed, saying that people who can, *should* be allowed to live in their own homes. Unnecessary institutionalization, the court continued, falsely showed that people with disabilities cannot actively participate in their own communities.

Living in one's own community is a human civil right that *everyone* has. Since the 1990s, Congress has passed laws that have created different HCBS programs, allowing people to live in their homes.

### **Money Follows the Person (MFP)**

One such service, or program, is MFP. It helps people move from an institution to a house or an apartment of their own. Here, it's known as Idaho Home Choice (IHC). It provides individuals who are elderly or who have an ID/DD with more informed choices and options about where they could live and receive services. It also allows people to choose their service providers, express their satisfaction or dissatisfaction with services and supports, visit with family and friends and be a part of their community. MFP helps individuals like me receive long-term care in their own homes and increases independence.

MFP was first authorized in the Deficit Reduction Act of 2005. It was strongly supported by both Democrats and Republicans and signed into law by President George W. Bush. Since its beginning, 47 states have participated and over 75,000 individuals have been moved from institutions into their communities.

The MFP program expired nationally on September 30, 2016. It is up for renewal, but some states are already out of money, while others are using remaining funds through 2020. These states are more mindful of how this money is spent. They have begun reducing staff and resources.

In December 2017, Senators Rob Portman (R-OH) and Maria Cantwell (D-WA) introduced the EMPOWER Care Act to reauthorize MFP. This Act would:

- A. Extend MFP through 2022
- B. Remove barriers that keep people institutionalized
- C. Enhance states' accountability and
- D. Contribute to the sharing of better ideas between states on how to use MFP.

These changes would shorten the institutional stay of people with ID/DD from 90 days to 60 days before a person is eligible for MFP. The changes should increase the number of individuals eligible for MFP. They will also help states lower the costs for Medicaid programs. In addition, the EMPOWER Care Act is expected to increase opportunities for individuals to live independently and age with dignity living at home.

### **Advocate for Your Rights**

States using MFP have made great progress, however, more work is needed. As of April 12, 2016, Idaho has helped 350 people move into homes in their communities. Reauthorizing MFP would help even more people leave institutions. To help your state and others in disability advocacy encourage legislators to renew MFP:

### **Tell your story**

Faces matter, because when you put a face to your name, you become someone to state agencies and legislators, and not just another case. With Medicaid undergoing changes and the country facing budget cuts, some services will be changed while others will be stopped.

### **Talking Points**

- 1) If it's not renewed, many people with ID/DD will remain in institutions, or some may be removed from their homes and put into institutions.
- 2) Institutions costs states more money. Living in the community is cheaper than being in an institution.

To share your story and help self-advocates and others who want to see MFP renewed, contact your legislators. You can Google your state's legislative website or ask friends or family

members to help you look it up. There, you can find their phone numbers and email and important background information.

While closing institutions is still a work in progress across the United States, the trend of allowing people with disabilities to live in their own communities gives us hope for a better future.

## References

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