

UNITED SPINAL^{NOW}

Biden Era Caregiving

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The sleeping giant, i.e. the need for enhanced home- and community-based services, is awakening. The Biden Administration, in keeping with a campaign promise, intends to consider the collective-care needs of our country, basically from “womb to tomb.”

Including infant care, childcare, after-school care, care for people with disabilities and seniors, this comprehensive look at care giving and care needs is a once in generations opportunity for people with disabilities to improve their ability to live in the community. It is also an opportunity to seek fair remuneration for home-care workers and personal care attendants (PCAs).

Those needing care in the disability community range from those who are physically, emotionally and intellectually incapable of caring for themselves, to emotionally and intellectually capable but physically reliant on a caregiver for assistance with activities of daily living. The latter group need the ability to manage their personal care attendants and any new plan should provide for consumer-controlled care.

The plan to deliver home- and community-based services to people with disabilities should encourage work. For decades, poverty was required (Medicaid eligibility) to receive homecare. Work incentive programs rarely allow for the ability to accumulate wealth and/or be entrepreneurial. People with disabilities with the ability to support themselves rarely make enough to pay for homecare privately, especially those just entering the labor force.

Family caregivers are a mainstay of support and care for people with disabilities. The Biden Administration plan should lessen the financial burden on family caregivers. Americans don't realize how difficult it is to obtain and afford long-term care, reside in the community – instead of a nursing home – or work with a disability that requires assistance with dressing, meals and personal care, until they or someone they love confront these problems.

Remember, the Administration is talking about all care giving, not just care for people with disabilities. Our community's needs are nuanced. Representatives of groups of varying types of people with disabilities with care needs must be at the table to ensure that each group can take advantage of a new care scheme.

Rest-assured, labor groups will be at the table. They have worked hard to ensure that homecare workers were finally included in the Fair Labor Standards Act (FLSA) minimum wage and overtime provisions. They are also pushing hard for a national \$15 an hour minimum wage. In some areas of the country, this will force Medicaid-provided homecare hours to be cut, unless there is an increased appropriation by government for care. This would have the ridiculous effect of forcing people into nursing homes, which cost far more per person than homecare.

Those of you reading this with personal care needs understand the fragility of the current system (and New York's is better than most). Those whose lives depend on reliable, responsible care by trained, compassionate care providers appreciate when the system works, and panic when it doesn't.

Many of United Spinal's members and many readers have developed relationships with PCAs and consider them family. The Administration should find a way to acknowledge these relationships and allow for live-ins and hiring by the consumer of care.

Two other wide-awake giants in the United States are immigration and working-class unemployment. Americans born today will live and work longer than any generation in world history. They will need home- and community-based services to remain productive and healthy. There's a match here. Homecare worker does not have to be employment of last resort. It can attract those with career ambitions and the desire to be upwardly mobile. Benefits and paid-time off with opportunities to advance in employment will make the job a vocation.

In the coming months, we will hear from organized labor about this issue. Homecare workers need protections. We will support the workers, just as we will seek their support for adequate home and personal care services that incentivize work and can be consumer-controlled.