New CMS Guidance Expands Options for Adults with I/DD

Gated communities, farms and clustered housing no longer presumed "segregating."

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On Friday, March 22, 2019, the Centers for Medicare and Medicaid Services (CMS) issued new guidance that promises to change the landscape of residential settings available to adults with intellectual and developmental disabilities (I/DD). It’s not easy to excite the public over federal regulations in general, never mind those issued by the Centers for Medicare and Medicaid Services (CMS). But this is big news: the National Council on Severe Autism called it “a significant policy victory”. Desiree Kameka, the National Coordinator of the Coalition for Community Choice, agreed, “The impact of this change cannot be understated.”

Currently, many states – such as Pennsylvania, where I live – refuse to fund any residential setting for people with I/DD larger than three or four people. State disability offices have justified this shockingly discriminatory practice – those without disabilities can and do choose to live in all kinds of peer-specific settings, including retirement communities, college dorms, and religious enclaves – by appealing to previous guidance issued by CMS. This communication explicitly targeted farmsteads, gated communities and clustered housing as presumably non-compliant with the agency’s 2014 Final Rule, which aimed to end the isolation and segregation of adults with I/DD.

This is a critical and uncontroversial goal. But where it got sticky was in the definition of these terms. Is 20 people with autism living together “segregation” or “community”? And who decides? Largely due to the influence of a vocal minority of inclusion advocates, “institution” has been redefined as “more than four unrelated people” (for context, keep in mind that Willowbrook had 6000 residents). In practice, this has come to mean evaluating policies solely in terms of how many neurotypical people any individual person with I/DD lives and works with – whether or not that “inclusive” setting is desired or even appropriate.

Recent reviews of the literature confirm that regulations such as these are fueled more by ideology than data. David Mandell, ScD., Director of the Center for Mental Health Policy and Services Research at the University of Pennsylvania, concluded, “Right now, our decision-making regarding which types of placements to pay for and prioritize is based on values rather than data.” Which is why the effort to increase the choices available to this population has enjoyed such broad support – not only from families and providers (65 disability organizations from across the country signed a letter to CMS in April 2018 urging the retraction or replacement of the original guidance), but from disabled people themselves. As John Elder Robison – a prominent autistic self-advocate and member of the Interagency Autism Coordinating Committee (IACC) – told me, “Safety is an important concern for our community, but it should be treated as independent of residential setting. Abuse and neglect can happen anywhere – I was abused as a child in my own home.” He added that he could completely see the appeal of farms or other
communities for autistics. “What’s important,” he emphasized, “is the availability of a wide range of safe, supported choices, with each individual having the maximum amount of self-determination.”

Besides removing the stigmatizing language, the new guidance stresses the importance of person-centered planning and affirms CMS’ commitment to outcomes, rather than the physical characteristics of settings. Kameka celebrated the “unnecessary barriers” removed by the new guidance, and anticipates the growth of a range of new projects, catering both to adults with I/DD who prefer to live with peers, as well those with more significant medical and behavioral challenges, whose needs cannot be safely met in small, dispersed settings.

The battle isn’t over yet. States are free to adopt more restrictive criteria than those identified by CMS, so the fight now shifts to the individual state disability offices. But, now that a key pillar supporting these restrictive policies has been removed, Kameka expects the entire edifice will soon topple. “This shows the power of advocacy,” she told me. “The voices of people with disabilities were brought to light – they fought the hardest for the right to live in homes that would be available to those who are neurotypical. This new guidance should remove a lot of confusion, fear, and anxiety.”

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