

Adults with disabilities on Medicaid wait list most likely to have unmet service needs

October 6 2016, by Sharita L Forrest



A survey of caregivers for adults with intellectual and developmental disabilities on Illinois' Medicaid wait list found disparities in the provision of services. The study was co-written by University of Illinois scholars Meghan M. Burke, a professor of special education at the Urbana campus, and Tamar Heller, the head of the University Center for Excellence in Developmental Disabilities Education at the Chicago campus. Credit: L. Brian Stauffer

Adults with intellectual and developmental disabilities on Illinois' Medicaid wait list who are minorities, in poor health or unable to speak are more likely to have unmet service needs, a new study found.

African-Americans had a greater number of unmet service needs than whites, as did people with annual household incomes below \$50,000 and those who were less healthy or had less verbal ability, according to a new statewide survey of 230 caregivers.

That these clients are not receiving needed services - including preventive health care, dental services and physical therapy - is worrisome and suggests there may be disparities that need to be addressed with policy, said the paper's lead author, Meghan M. Burke, a special education professor at the University of Illinois.

Burke conducted the survey with Tamar Heller, a professor of disability and human development at the University of Illinois at Chicago. Heller, the principal investigator for the project, is director of the U. of I. University Center for Excellence in Developmental Disabilities Education.

About 20,000 people currently are on Illinois' wait list for services under the Medicaid Home and Community-Based Services waiver, which reimburses states for providing support services such as [health care](#), therapies and employment.

One of the purposes of the survey, Burke said, was to examine the characteristics of individuals on the wait list to determine which clients were in the greatest need of services. A paper about Burke and Heller's findings was published recently in the *Journal of Applied Research in Intellectual Disabilities*.

The survey was part of an evaluation of the Ligas Consent Decree, the

outcome of a recent class-action lawsuit involving nearly 11,000 Illinois adults with intellectual and [developmental disabilities](#). Under the tenets of the decree, the Illinois Division of Developmental Disabilities agreed to expeditiously serve people on the wait list who met established crisis criteria and to move everyone off the wait list by 2017.

Younger caregivers in the survey reported significantly greater unmet service needs than did older caregivers. However, Heller noted that younger parents have higher expectations, as they're accustomed to their children receiving free services through the special-education system. Heller found similar results in a study she conducted with families on wait lists in Minnesota.

Transitioning from receiving services through the school system to obtaining those services from community agencies can be challenging for family caregivers when children with intellectual and development disabilities reach adulthood, Burke said.

"There's no mandate to ensure that individuals get services such as speech therapy once they age out of the school system," Burke said.

While schools in the U.S. are required to develop transition plans for students with disabilities when they prepare to leave school, those plans are often vague and generic. A recent study of 282 student-transition plans found that less than a third of the plans connected families with adult-services agencies in their communities, the researchers wrote.

Burke and Heller said greater interagency collaboration between schools and adult service providers is needed, and community agencies' representatives need to be included in the transition-planning process.

"Practitioners and policymakers may want to look at the provision of services through the special-education system to determine how to

address these service disparities among adults," Burke said.

More information: Meghan M. Burke et al, Disparities in Unmet Service Needs Among Adults with Intellectual and Other Developmental Disabilities, *Journal of Applied Research in Intellectual Disabilities* (2016). [DOI: 10.1111/jar.12282](https://doi.org/10.1111/jar.12282)

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