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Report: Poverty Higher, Care Less Coordinated For Kids With Intellectual Disabilities
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DURHAM, N.H. –Children with autism spectrum disorder, Down syndrome, and intellectual disabilities are more likely to live below the federal poverty line and less likely to receive coordinated care services than children with other special health care needs, a new report by a University of New Hampshire research team finds. The report, published this month in the journal Pediatrics, examines access to genetic counseling services for families of children with these three genetically derived disabilities.

"With the number of kids born with some of these conditions, particularly autism spectrum disorders, on the rise, we wanted to see whether families are getting access to the services they need and, if not, why not. What are the disparities?” says lead author Robert McGrath, assistant professor of health management and policy at UNH.

Genetic counseling is defined as “helping people understand and adapt to the medical, psychological and familial implications of genetic contribution to disease.” Recommended for families of children with Down syndrome, autism spectrum disorder (ASD), and intellectual disabilities, genetic counseling can serve as a gateway to a full range of educational, training, and testing support as well as additional medical services.

"The big findings were that children who had a medical home – a place where they could go for regular care – were almost three times more likely to get all the genetic counseling services they needed,” says McGrath. Yet only 30 percent of families of children with these conditions reported having a medical home such as a primary care physician or another regular, coordinated source of care. “These kids who need the coordination the most, they get it the least,” McGrath added.

Using data from the 2005-2006 National Survey of Children with Special Health Care Needs, researchers found that parents of children with one of these three conditions reported a significantly higher need for genetic counseling services (GCS) than families of other children with special health care needs: 14 percent versus 4.3 percent.

The researchers also found that children with Down syndrome, ASD, and intellectual disabilities (also referred to mental retardation) were much more likely to be poor (27.4 percent living below the federal poverty level) compared to other children with special health care needs (18.1 percent living below the poverty line).

"The big question is, is it the condition that’s impoverishing these families, or are these conditions disproportionately affecting the poor?” says McGrath, who strongly suspects the former. “As the prevalence of these conditions goes up, you’re going to find more and more people either impoverished or burdened by having a child with one of these conditions.”
The findings point to a need for shifting priorities in the care and treatment of children with these conditions. “More treatments aren’t going to do a lot of good if people can’t get access to them,” says McGrath.


In addition to McGrath, UNH co-authors are David Laflamme, research assistant professor of health management and policy and maternal and child health epidemiologist for the New Hampshire Division of Public Health Services; Amy Schwartz, associate director and clinical assistant professor of the New Hampshire Institute for Health Policy and Practice; Michelle Stransky, doctoral candidate in the department of sociology; and John Moeschler, M.D., principal investigator for the New England Genetics Collaborative at UNH’s Institute on Disability and professor of pediatrics at Dartmouth Medical School.

The report was developed with support from the New England Genetics Collaborative, funded by a federal cooperative agreement from the U.S. Department of Health and Human Services.

The University of New Hampshire, founded in 1866, is a world-class public research university with the feel of a New England liberal arts college. A land, sea, and space-grant university, UNH is the state's flagship public institution, enrolling 12,200 undergraduate and 2,200 graduate students.

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