State-to-State Variation in SSI Enrollment for Children With Mental Disabilities: An Administrative and Ethical Challenge

Kimberly E. Hoagwood, Ph.D., Bonnie T. Zima, M.D., M.P.H., Stephen L. Buka, Sc.D., Amy Houtrow, M.D., Kelly J. Kelleher, M.D., M.P.H.

Objective: The study examined state variation in rates of Supplemental Security Income (SSI) determinations, allowances, and receipt of benefits for ten selected child mental disabilities in 2013.

Methods: SSI administrative and U.S. Census Bureau data collected by a multidisciplinary consensus committee convened by the National Academies of Science, Engineering, and Medicine in 2015 were examined.

Results: Less than 1% of children in 2013 were recipients of SSI for mental disabilities. Determination rates ranged from 1,441 to 251 per 100,000 low-income children, an almost sixfold difference. Allowance rates varied from 16% to 78%, a fivefold difference. Receipt of benefits ranged from .7% to 5.3%, a sevenfold difference.

Conclusions: Large unexplained discrepancies across states were found in review and receipt of SSI benefits for lowincome children with mental disabilities. Inequities that cannot be explained by disability severity or financial need violate the ethos of equitable access to federally entitled services.

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The Supplemental Security Income (SSI) program is one of the few federal programs to provide monthly cash assistance to low-income families of children with mental disabilities that result in severe impairment. SSI eligibility often improves access to mental health services because it ensures referral to state Title V programs and, in most states, qualifies children for Medicaid.

The prevalence of child psychiatric disorders has been relatively constant (1). Thus an increase in the number of children receiving SSI benefits for attention-deficit hyperactivity disorder (ADHD) in recent years has led to media attention and a Government Accountability Office report (2). In response, the Social Security Administration commissioned the National Academies of Science, Engineering, and Medicine (NAS) to examine recent growth in the number of low-income children with mental disabilities served by the SSI program (3). The full report describes features of the national context that may contribute to the rise in SSI benefits for these children (4). Summaries of the main results of this report are also available (5-9).

Federal entitlement programs, such as SSI, provide personal financial benefits to beneficiaries who have a legal right (enforceable in court, if necessary) whenever they meet eligibility conditions that are specified by the standing law that authorizes the program. There are few entitlement

programs for children with mental disabilities. These children are known to be significantly underserved (10). Eligibility for benefits has the potential to equalize access to services. State-to-state variations in administration of entitlement programs raise fundamental ethical as well as practical questions about why eligibility should differ on the basis of state residence. Therefore, the objectives of this study were to examine variation by state in the rates of SSI determinations, allowances, and receipt of benefits for ten selected childhood mental disabilities as of 2013 and to describe ten-year trend data (2004-2013) in SSI determination rates among low-income children (those living in households below 200% of the federal poverty level (FPL). (SSI uses the term "mental disabilities." These include psychiatric or mental disorders as well as developmental and intellectual disabilities. We use the term "mental disabilities" in this report to be consistent with SSI terminology.)

METHODS

The NAS committee focused on ten mental disabilities: ADHD, oppositional defiant disorder, conduct disorder, autism spectrum disorders, intellectual disability, borderline intellectual function, mood disorders, learning disabilities, organic mental disorders, and anxiety-related disorders.

FIGURE 1. Percentages of children in low-income households who were 2013 recipients of Supplemental Security Income benefits for ten mental disorders^a



^a Source: National Academies of Sciences, Engineering, and Medicine; reprinted with permission

These were selected because they are the highest-frequency diagnoses associated with SSI allowances and are included in the SSI list of mental disabilities.

Data on SSI determinations, allowances, and recipients for these ten disabilities from 2004 to 2013 were provided by the Office of Disability Policy Management Information and the Office of Research, Evaluation, and Statistics. Determinations refer to the total number of applications reviewed to determine whether an applicant meets financial eligibility and criteria for severe impairment. Allowances refer to the percentage of determinations in which the individual was found to be severely disabled. The term "recipients" refers to all children who were cumulatively eligible during a given year—that is, who were newly deemed or continued to receive cash assistance, irrespective of when they became eligible.

The absolute number of determinations and recipients varies between states because of differences in state population sizes and the number of low-income children in each state. Accordingly, we generated state-specific rates, taking into consideration both the total population size and the estimates of the number of low-income families, by using data from the U.S. Census Bureau 2015 Current Population Survey. For each state, we estimated the number of children under age 18 and living in households below 200% of the FPL (from 2004 to 2013) as a proxy for the number of children who were incomeeligible for SSI. This served as the denominator to calculate state-specific determination, receipt, and eligibility rates in 2013.

RESULTS

The 2015 NAS report, *Mental Disorders and Disabilities Among Low-Income Children*, found that approximately 1.3 million children received SSI disability benefits in 2013,

representing 1.8% of all U.S. children (3). Of these beneficiaries, about 50% received benefits as a result of mental disabilities.

State-specific rates of determinations for the ten mental disabilities varied by a factor of 5.7, ranging from a high of 1,441 per 100,000 income-eligible children in Pennsylvania to a low of 251 per 100,000 in Nevada. [A figure in an online supplement to this report presents these data.]

The rate of determinations also varied, with western states lower than eastern states. A cluster of states with low determination rates was found in southeastern states, whereas high determination rates clustered in northwestern and western states.

In Georgia, 16% of applications for SSI benefits for the ten mental disorders were approved, in contrast to 78% in Alaska, a fivefold difference. Nationally, this rate aver-

aged 37%; it was greater than 50% in 13 states and less than 25% in seven [see online supplement].

The percentage of low-income children who are recipients in a state is an indicator of the coverage of the SSI program for children with severe mental disabilities in that state. In 2013, .7% of low-income children were recipients in Hawaii, and 5.3% of low-income children were recipients in Pennsylvania; this is a 7.6-fold difference [see online supplement].

Figure 1 is a map of the variations in percentages of poor children who were recipients of benefits for the selected mental disabilities across states.

Between 2004 and 2013, the average annual rate of determinations for low-income children in the United States decreased 2%. Here again, there were significant state variations. The rate of determinations in Rhode Island increased by 48%, from 584 per 100,000 low-income children in 2004 to 864 per 100,000 in 2013. In Utah and Texas, it increased by 32%, and in Connecticut, it increased by 31%. In other states, such as Minnesota, North Dakota, Kansas, and Nevada, the determination rate decreased by at least 33% [see online supplement].

DISCUSSION

The NAS committee was not asked to nor did it examine the reasons for the large discrepancies across states. Nevertheless, the administrative data provided by the SSA show wide variation by state in determination, allowance, and receipt rates of SSI benefits for child mental disabilities. Ten-year trends in determination rates also varied substantially across states. The probable consequence of these inconsistences is that the likelihood of receiving SSI benefits for children with severe mental disabilities depends on the state of residence: a child is likely to become a recipient of SSI benefits if he or she lives in one state but will be denied benefits if he or she

lives in another. This is an inequity in both the spirit and the implementation of this federal entitlement program.

Variations have been found in other service programs for children with health and mental health needs. For example, an analysis of data from the 2007 National Survey of Child Health found a threefold difference in rates of child mental health issues between states with the highest and lowest rates (11). Similarly, variations in rates of special education services for emotional disturbance—as defined by IDEA education legislation, a federal entitlement program for special education services-differed 33-fold across states (12,13). This variation occurred despite a federally mandated definition of emotional disturbance.

It is important to note that the issue of inequity is different from the issue of low or high rates. It is unknown what the "correct" rate of determinations, allowances, or receipt for SSI benefits might be. Although estimates of the prevalence of each of the ten mental disabilities are discussed in the NAS report, the issue of equity in implementation is different from the issue of whether a rate is low or high.

Nevertheless, these variations violate the spirit of federally mandated programs for children with special needs. Factors that may contribute to this variation include differences in the determination process, state policies, and external factors outside the administration of the SSI program. The process of determining eligibility for services in the SSI program is unique and is not based on standardized measures of diagnoses and impairment that are often used in epidemiologic studies or national surveys of child health. When a parent applies for and is given a tentative diagnosis, SSA develops a case portfolio, based on medical and other records, to confirm or change the diagnosis and to determine whether it meets the SSA-defined definition of disability. These evaluations are carried out at the state level by state Disability Determination Services (DDS). Although states use national standards with oversight by the SSA, they do not physically examine the child, although they may request examinations and testing. Furthermore, an assessment of severity is necessary to determine the extent of the disability, irrespective of the specific diagnosis. Those who apply for SSI often have multiple disabilities, and it is often easier to make the determination on the basis of one rather than another. This process itself may contribute to inconsistencies in implementation of program requirements.

In 2015, the Office of the Assistant Secretary for Planning and Evaluation of the U.S. Department of Health and Human Services examined state variations in SSI pediatric caseloads (14) and concluded that regional, state, and local factors likely influenced program growth. Factors that might affect the variation included advocacy groups and their power to influence policies, differences in state economies that affect the opportunities of parents and youths to obtain public assistance, demographic variations, and state DDS review processes, which provide latitude in compensation, hiring of examiners, and use of private contractors.

It is also possible that state-specific policies affecting implementation of public benefit programs may influence state rates. For example, SSI benefits may be substituted for Temporary Assistance for Needy Families (TANF) benefits in some states, and TANF uses state dollars. Prior analyses by SSA of adult allowance rate variation suggest that about half of the variation might be explained by factors external to the program, such as numbers of applications and insurance coverage.

CONCLUSIONS

Given that income supports are likely to improve long-term mental health outcomes for children (15), interventions to ensure greater consistency in the implementation of the SSI program may have a large effect on the future health of children with mental disabilities living in poverty. There is an ethical argument for ensuring that the spirit of federal entitlement programs is reflected in more equitable access to these programs. Eligibility and receipt of benefits should depend not on state residency but rather on consistent implementation of program benefits.

AUTHOR AND ARTICLE INFORMATION

Dr. Hoagwood is with the Department of Child and Adolescent Psvchiatry, NYU School of Medicine, New York City (e-mail: kimberly. hoagwood@nyumc.org). Dr. Zima is with the Center for Health Services and Society at the David Geffen School of Medicine, University of California, Los Angeles. Dr. Buka is with the Department of Epidemiology, Brown University, Providence, Rhode Island. Dr. Houtrow is with the Department of Physical Medicine and Rehabilitation, University of Pittsburgh School of Medicine, Pittsburgh. Dr. Kelleher is with the Research Institute of the Center for Innovation in Pediatric Practice, Nationwide Children's Hospital, Columbus, Ohio

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REFERENCES

- 1. Angold A, Erkanli A, Copeland W, et al: Psychiatric diagnostic interviews for children and adolescents: a comparative study. Journal of the American Academy of Child and Adolescent Psychiatry 51:506-517, 2012
- 2. Supplemental Security Income: Better Management Oversight Needed for Children's Benefits. GAO-12-497. Washington, DC, Government Accountability Office, June 26, 2012
- 3. National Academies of Sciences, Engineering, and Medicine: Mental Disorders and Disabilities Among Low-Income Children. Washington, DC, National Academies Press, 2015. http://iom.nationalacademies.org/ Reports/2015/Mental-Disorders-and-Disabilities-Among-Low-Income-Children.aspx
- 4. Boat TF, Buka SL, Perrin JM: Children with mental disorders who receive disability benefits: a report from the IOM. JAMA 314: 2019-2020, 2015
- 5. Kelleher KJ, Stein REK, Hoagwood KE: Supplemental Security Income for children with mental disabilities. Pediatrics 2016 (doi: 10.1542/peds.2015-3342)
- 6. Kelleher KJ, Boat TF, Houtrow AJ, et al: Poverty and Supplemental Security Income: can DBPs take a more active role? Journal of Developmental and Behavioral Pediatrics 37:267-268, 2016

- 7. Hoagwood KE, Kelleher K, Zima BT, et al: Ten-year trends in treatment services for children with attention deficit hyperactivity disorder enrolled in Medicaid. Health Affairs 35:1266-1270, 2016
- 8. Houtrow AJ: At the intersection of poverty and disability: Supplemental Security Income for children with disabilities due to mental health problems. Archives of Physical Medicine and Rehabilitation 96:2094-2095, 2015
- 9. Perrin JM, Houtrow A, Kelleher K, et al: Supplemental Security Income benefits for mental disorders. Pediatrics, 2016 (doi: 10.1542/
- 10. Kataoka SH, Zhang L, Wells KB: Unmet need for mental health care among US children: variation by ethnicity and insurance status. American Journal of Psychiatry 159:1548-1555, 2002
- 11. Ghandour RM, Kogan MD, Blumberg SJ, et al: Mental health conditions among school-aged children: geographic and sociodemographic patterns in prevalence and treatment. Journal of Developmental and Behavioral Pediatrics 33:42-54, 2012

- 12. 37th Annual Report to Congress on the Implementation of the Individuals With Disabilities Education Act. Washington, DC, US Department of Education, Office of Special Education and Rehabilitative Services, Office of Special Education Programs, 2015
- 13. Students ages 6-21 identified as having emotional disturbance in the 50 states and the District of Columbia. Washington, DC, US Department of Education, Office of Special Education Programs, 2015. http://cecp.air.org/resources/20th/figII-10.asp. Accessed Feb
- 14. The Child SSI Program and the Changing Safety Net. Washington, DC, US Department of Health and Human Services, Office of the Assistant Secretary for Planning and Evaluation, Office of Human Services Policy, 2015
- 15. Costello EJ, Compton SN, Keeler G, et al: Relationships between poverty and psychopathology: a natural experiment. JAMA 290: 2023-2029, 2003

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