

February 2, 2018

Katherine Bent  
Associate Commissioner for Research, Demonstration, and Employment Support  
Office of Employment and Disability Policy  
Social Security Administration  
6401 Security Blvd.  
Baltimore, MD 21235-6401

RE: Docket No. SSA-2017-0049

Dear Ms. Bent,

We the undersigned organizations are pleased to submit comments in response to the Social Security Administration's (SSA's) Request for Information on Strategies to Improve Adult Outcomes for Youth Receiving Social Security Income (SSI). We commend the SSA for directing greater attention to the distinct needs of transition-age youth and young adults, ages 14 to 25.

There is substantial evidence, as you know, documenting the challenges that this population group faces during transition, as exemplified by the concerning finding that SSA's redetermination of SSI eligibility at age 18 results in 30-40% of youth losing eligibility. Not only are transition-age youth with disabilities confronting a high risk of losing their SSI eligibility and associated automatic Medicaid coverage, many are also confronting major shifts in other public program eligibility, such as in state Title V Programs for Children with Special Health Needs (where childhood eligibility ends typically at 21, with no corresponding adult program), in state Mental Health Block Grant Programs (where eligibility as a child typically ends at 18 and more restrictive eligibility rules apply as an adult), and in state Developmental Disabilities Programs (where similar restrictive adult eligibility policies exist for those typically over age 18). Further complicating these critical public program eligibility issues is the lack of preparation that youth with special health care needs receive about their transition from pediatric to adult health care. According to the 2016 National Survey of Children's Health, 87% of parents who have youth with special health care needs, report that they did not receive transition preparation from their health care providers.<sup>1</sup> Clearly, navigating the maze of changes that take place during the transition years are daunting for all youth, but especially for those with disabilities as they attempt to qualify as an adult for various public program services.

Our comments, which are organized according to your questions, are offered in light of our expertise in health and focus on strengthening SSA policies, information, and demonstrations for transition-aged youth and young adults. Evidence shows that youth and young adults with chronic conditions who stay connected to health care have better education and employment outcomes than their peers without insurance protections or a usual source of care.<sup>2-9</sup> Since young adults with disabilities are disproportionately affected by poverty and adverse social determinants of health, creating stability in public program eligibility, health insurance coverage, and primary care during this challenging transition period can go a long way to building a solid foundation for employment in adulthood.

1. *What should SSA's role be in assisting the transition of youths to adulthood and coordinating with other agencies' transition efforts?*

SSA has played a key role in the federal interagency strategy for youth transitions, including the 2020 Federal Youth Transition Plan.<sup>10</sup> With respect to health, this plan calls for equal opportunities for youth with disabilities to access health services and to receive health care management support. The plan also calls for greater interagency collaboration. Among the 12 future policy areas listed in the plan, only 2

pertain specifically to health: 1) access to quality health care and health insurance, and 2) professional development for health care providers to build competencies in asset-based service delivery approaches. The examples of federal strategies in action described in the plan mostly showcase partnerships around employment and education, not around health. We recommend that SSA and the Federal Partners in Transition Work Group expand their efforts to include health in all of their transition initiatives. Got Transition, the national resource center on health care transition, funded by HRSA's Maternal and Child Health Bureau, and state Title V programs for children with special health care needs can be called on to assist SSA and other federal transition partners with building a stronger health foundation, consistent with the recommendations of the AAP/AAFP/ACP Clinical Report on Health Care Transition<sup>11</sup> and the Standards for Systems of Care for Children and Youth with Special Health Care Needs.<sup>12</sup>

*2. Do SSA's policies need to be modified to improve use of services and supports?*

We recommend that SSA modify its income and asset restrictions, allowing transition-aged youth and young adults to save more money for their education or put into their PASS account. We also recommend that SSI remove the requirement that for every \$2 made, \$1 must be returned. Given the poverty status of SSI recipients, taking away this money penalizes recipients for being employed and interferes with their ability to be independent and provide improved quality self-care.<sup>13</sup>

*3. Are there aspects of SSA's publications and information that can better support successful transitions to adulthood of youths receiving SSI?*

We recommend that a comprehensive set of informational resources and a new benefits counseling strategy be developed which focuses on transition-aged youth and young adults, including but not limited to the SSI redetermination process. Current SSA information for this transition age group is extremely limited. We found only one SSA brochure, "What You Need To Know About Your SSI When You Turn 18." We recommend that a SSI benefits counseling strategy for this age group incorporate specific outreach, training, publications, webinars, and telephone assistance and link with existing care coordination systems, family navigation initiatives, and peer mentoring programs operated by health and mental health programs (e.g., state Title V agencies, health homes), among others. In addition, we recommend that more specific information be made available as part of this benefits counseling about Medicaid and the importance of transitioning to an adult primary care provider. Further, we suggest that during the SSI redetermination process, that recipients receive detailed information about how to apply for and access SNAP benefits.

*4. If SSA were to conduct a new demonstration project related to youth, which populations should SSA consider targeting?*

We recommend that SSA consider the following research and demonstration efforts.

1. With HHS partners, develop a comprehensive benefits "counseling change package" that incorporates essential information for transition-aged youth and young adults and their families about SSI, health insurance coverage and continuity of care, school options, work incentives, SNAP benefits, and savings. With this new "change package," we recommend that SSA (and other federal partners) conduct a learning collaborative with at least 5 states, involving key stakeholder groups (e.g., local SSA office, Medicaid, Title V, Vocational Rehabilitation, special education, benefits counselor, and family-led organization) working together to pilot this coordinated benefits counseling strategy using formal quality improvement methods, refining as necessary, and developing an implementation and evaluation strategy that all states can use.
2. Conduct a demonstration project that establishes a coordinated transition strategy across public programs serving youth and young adults with disabilities as they move from child to adult

program eligibility without disrupting their access to health care and community-based supports. These programs could include SSI, Medicaid, Title V, special education, mental health, developmental disabilities, and vocational rehabilitation.

3. Conduct a cost effectiveness study on the impact of retaining SSI and Medicaid coverage through age 21 compared to SSA's current policies.
  4. Conduct a study analyzing what proportion of young adults who lose SSI coverage also become uninsured.
  5. Conduct an analysis of state variability in SSI redeterminations for transition-aged youth, identifying disparities by diagnosis and disability.
5. *Are there entities we could look at as exemplars based on current practices for serving youth with disabilities? What evidence exists to suggest these sites are effectively providing services that would lead to the increases self-sufficiency of youths with disabilities?*

We recommend that SSA examine the Six Core Elements of Health Care Transition,<sup>14</sup> which are part of the National Standards for Systems of Care for Children and Youth with Special Health Care Needs,<sup>12</sup> as a best practice in health care transition. Got Transition, the HRSA/MCHB-funded resource center, has developed a nationally recognized approach for transition for use by health providers, care coordination programs, public health systems, and health plans. The Six Core Elements of Health Care Transition has been widely tested in quality improvement initiatives and can be easily customized for use by various types of programs. For more information, please visit [www.gottransition.com](http://www.gottransition.com). We also want to share with SSA the evidence showing that having a structured health care transition intervention results in improvements in adherence to care, self-care skills, and consumer experience and reductions in emergency room and hospital use.<sup>15</sup>

6. *Since most children are in school, what outcomes or milestones should a program that included payments for child outcomes be tied to?*

We recommend that SSA consider adding the following health outcomes:

1. Every SSI recipient should have a primary care provider (PCP) as his/her usual source of care,
  2. Every SSI recipient should have made a PCP visit for preventive or chronic care in the past year.
  3. Every SSI recipient should have health insurance coverage.
7. *How should the age-18 redetermination and the fact that over one third of age-18 redeterminations result in the cessation of benefits because they do not have a condition that meets the adult disability factor into such a program?*

We recommend that SSA consider extending the age for SSI redetermination from 18 to 21. There are several arguments for retaining childhood SSI eligibility status for at least three additional years. The child disability definition, which emphasizes functional limitations is more developmentally appropriate for 18-21 year olds compared to the adult disability definition, which emphasizes inability to engage in substantial gainful activity. Many young adults between the ages of 18-21 are still in school and not in the workforce. Since as many as 19 states have not expanded Medicaid for low-income adults, the loss of SSI eligibility in these states places this poor population at substantial risk of being with no insurance. With three additional years of eligibility, young adults, ages 18-21, would also be in a better position to understand the process and requirements for redetermination.

Please do not hesitate to contact Peggy McManus, the President of The National Alliance to Advance Adolescent Health and the Co-Director of Got Transition, for further information at [mmcmanus@thenationalalliance.org](mailto:mmcmanus@thenationalalliance.org).

The National Alliance to Advance Adolescent Health  
African Caribbean American Parents of Children with Disabilities  
American Academy of Pediatrics  
Association of Maternal & Child Health Programs  
Autism Society of America  
Center for Innovation in Social Work and Health, Boston University  
Family Based Services Association (NJ)  
Family Voices of California  
Family Voices National  
Family Voices of New Jersey  
G.E.A.R. Parent Network (ME)  
Institute for Patient- and Family-Centered Care  
Lucile Packard Foundation for Children's Health  
Matrix Parent Network and Resource Center  
National Association of Pediatric Nurse Practitioners  
National Center for Parent Leadership, Advocacy and Community Empowerment  
National Council for Behavioral Health  
National Federation of Families for Children's Mental Health  
National PLACE  
NC Family to Family Health Information Center  
Parents' Place of MD  
Parents Reaching Out (NM)  
PEAK Parent Center (CO)  
PEAL Center (PA)  
Society for Adolescent Health and Medicine  
SPAN Parent Advocacy Network  
Texas Parent to Parent  
Total Family Care Coalition (DC)  
National PLACE Members:  
Advocates for Children of NYC  
Arkansas Waiver Association  
ASK Resource Center (IA)  
Association for Special Children and Families (NJ)  
Bayada (NJ)  
Connecticut Parent Advocacy Center  
Exceptional Children's Assistance Center (NC)  
FACT Oregon (OR)  
Family Connection of South Carolina  
Family Matters Parent Training and Information Center (IL)  
Family Network on Disabilities (FL)  
Family Resource Center on Disabilities (IL)  
Family Soup (CA)  
Family Voices of Wisconsin  
Federation for Children with Special Needs (MA)  
FIRST Parent Center (NC)  
Formed Families Forward (VA)  
INCLUDEnyc (NY)  
Long Island Advocacy Center (NY)  
Louisiana Parent Training and Information Center  
Maryland Coalition of Families  
Open Doors for Multicultural Families (WA)  
Parents CAN-Napa Valley Child Advocacy Network (CA)  
Parent Education Advocacy Training Center (VA)  
Parents Helping Parents (CA)  
Parent Network of Western NY  
Parents Let's Unite for Kids (MT)  
Parent to Parent of Georgia  
Parent to Parent of NJ  
Parent to Parent USA  
Rhode Island Parent Information Network  
Rowell Family Empowerment (CA)  
Starbridge (NY)  
Support for Families (CA)  
Washington PAVE  
West Virginia Parent Training and Information Center  
Wisconsin FACETS  
Wyoming Parent Information Center

## REFERENCES

1. Lebrun-Harris L, McManus M, Ilango S, et al. Transition preparation among youth with and without special health care needs in the United States. *Manuscript submitted to Pediatrics*. November 2017.
2. Butcher K. *Assessing the Long-Run Benefits of Transfers to Low-Income Families: Hutchins Center Working Paper #26*. Washington, DC: The Brookings Institution, January 2017. Available at: [https://www.brookings.edu/wp-content/uploads/2017/01/wp26\\_butcher\\_transfers\\_final.pdf](https://www.brookings.edu/wp-content/uploads/2017/01/wp26_butcher_transfers_final.pdf).
3. Cooper K, Stewart K. *Does Money Affect Children's Outcomes?* York, England: Joseph Rowntree Foundation, 2013. Available at: <https://www.jrf.org.uk/report/does-money-affect-children%E2%80%99s-outcomes>.
4. Ding W, Lehrer S, Rosenquist N, Audrain-McGovern J. The impact of poor health on academic performance: New evidence using genetic markers. *Journal of Health Economics*. 2009;28(3):578-597.
5. Duncan GJ, Magnuson K. The long reach of early childhood poverty. *Pathways*. Winter 2011.
6. Gurney JG, Krull KR, Kadan-Lottick N, et al. Social outcomes in the childhood cancer survivor study cohort. *Journal of Clinical Oncology*. 2009;27(14):2390-2395.
7. Pinzon Fonseca DA. *The Relationship between Health and Employment: Empirical study for USA*. Rotterdam, The Netherlands: Health Economics, Policy, and Law, Erasmus University of Rotterdam; 2011. Available at: <http://arno.uvt.nl/show.cgi?fid=122184>.
8. Ziol-Guest KM, Duncan GJ, Kalil A, Boyce WT. Early childhood poverty, immune-mediated disease processes, and adult productivity. *Proceedings of the National Academy of Sciences*. 2012;109 Suppl 2:17289-17293.
9. Maeng DD, Snyder SR, Davis TW, Tomcavage JF. Impact of a complex care management model on cost and utilization among adolescents and young adults with special care and health needs. *Population Health Management*. 2017;20(6):435-441.
10. Federal Partners in Transition Workgroup. The 2020 Federal Youth Transition Plan: A federal interagency strategy. 2015. Available at: <https://www.dol.gov/odep/pdf/20150302-fpt.pdf>.
11. Cooley WC, Sagerman PJ. Supporting the health care transition from adolescence to adulthood in the medical home. *Pediatrics*. 2011;128(1):182-200.
12. Association of Maternal & Child Health Programs, National Academy for State Health Policy, Lucile Packard Foundation for Children's Health. *Standards for Systems of Care for Children and Youth with Special Health care Needs (Version 2.0)*. Washington, DC: AMCHP, June 2017. Available at: <http://www.amchp.org/programsandtopics/CYSHCN/Documents/Standards%20for%20Systems%20of%20Care%20for%20Children%20and%20Youth%20with%20Special%20Health%20Care%20Needs%20Version%202.0.pdf>
13. Nicholas J. Prevalence, characteristics, and poverty status of supplemental security income multirecipients. *Social Security Bulletin*. 2013;73(3).
14. Six Core Elements of Health Care Transition. Available at: [www.gottransition.org](http://www.gottransition.org).
15. Gabriel P, McManus M, Rogers K, White P. Outcome evidence for structured pediatric to adult health care transition interventions: A systematic review. *Journal of Pediatrics*. 2017;188:263-269.