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Nancy Berryhill
Acting Commissioner
Social Security Administration
6401 Security Boulevard
Baltimore, MD 21235-6401

Submitted on www.regulations.gov

Re: Request for Information Regarding Strategies to Improve Adult Outcomes for Youth Receiving Supplemental Security Income (SSI)

Dear Acting Commissioner Berryhill:

The National Down Syndrome Congress (NDSC) is pleased to submit the following comments regarding the request for information regarding strategies to improve adult outcomes for youth receiving supplemental security income, 83 Fed. Reg. 411, published on January 3, 2018 [Docket No. SSA-2017-0049]. NDSC is the country's oldest and largest organization for people with Down syndrome, their families, and the professionals who work with them. NDSC, whose vision is a world with equal rights and opportunities for people with Down syndrome, provides support and information about issues related to Down syndrome throughout the lifespan and advocates for people with Down syndrome in matters of public policy. We appreciate this opportunity and are pleased to provide answers to certain of the questions posed in the RFI.

Question 1: What specific programs or practices have shown promise at the Federal, State, or local level in improving the adult economic outcomes of youth with disabilities receiving SSI?

NDSC recommends that SSA consider two promising best practices aimed at improving post-school outcomes, including education employment and economic self-sufficiency, for youth with disabilities. The best practices are higher education opportunities for students with intellectual disability (ID) and work-based learning.

Higher Education Opportunities for Students with Intellectual Disabilities

Employment outcomes for individuals with ID have historically been bleak. However, significant progress is being made through new higher education opportunities. There are now over 260

postsecondary programs for students with ID (see: www.thinkcollege.net). The Higher Education Opportunity Act of 2008 (HEOA) contained provisions to increase access to higher education for students with ID, including allowing the students to receive certain forms of federal financial aid and authorizing Transition and Postsecondary Programs for Students with Intellectual Disability (TPSIDs). These programs focus on academic enrichment, socialization, independent living, and employment in order to create, expand, or enhance high-quality, inclusive higher education experiences that lead to positive outcomes for individuals with ID. A National Coordinating Center (NCC) was authorized and awarded to the Institute for Community Inclusion at the University of Massachusetts Boston.

The NCC provides technical assistance, coordination and evaluation of the TPSID programs funded in 2010-2015 and again in 2015-2020 by the Office of Postsecondary Education, US Department of Education. The NCC reports data that reflect program characteristics, academic access, supports for students, and integration of the program within the Institution of Higher Education (IHE). Of particular note are the positive employment outcomes and trends over the 2010 through 2016 TPSID years, showing a significant improvement over the typically extremely poor employment outcomes for students with ID. In just six years, the TPSID initiative has supported the creation or expansion of programs at 88 colleges and universities serving 2,700 students with ID across 31 states. These students, who would otherwise have been likely to experience a lifetime of sheltered work or day habilitation, have been supported to take inclusive college classes, obtain career experiences through internships, and in many cases, have been given greater access to competitive integrated paid employment. The following employment data points illustrate very promising outcomes:

- The percentage of students with a paid job while participating in a TPSID from 2010-2016 began at 27% (2010-11) and increased to 43% (2015-16). The percentage of employment while in college is the same as the percentage of full-time undergraduate students without disabilities.
- Data from 2015-16 indicate that 43% of students had a paid job and 56% of these students had NEVER held a paid job prior to enrolling in the TPSID.
- Nearly two thirds of individuals who completed a TPSID initiative (62%) had a paid job one year after exit. In comparison, 17% of adults with ID in the general population had a paid job in the community in 2014–2015, the most recent year for which data are available (National Core Indicators, 2017).

Work-based Learning Experiences

Work-based learning experiences, such as internships, short-term employment, and apprenticeships, link knowledge gained at a work site with a planned program of study.¹ Work-based learning is a strong predictor of employment success for individuals with disabilities and

¹ What to Know about Work-Based Learning Experiences for Students and Youth with Disabilities [report](#), 2015

other populations with barriers to employment.² Research has found that work-based experiences lead to positive employment outcomes, including for students with significant disabilities.³ Work-based learning experiences were found to develop positive work habits, improve work and soft skills, promote independence and leadership skills, and increase employment success. The top two predictors of integrated employment 18 months after leaving public school were found to be family preferences for paid work and paid work during secondary school.⁴ The Department of Labor should ensure that childhood SSI beneficiaries are able and encouraged to participate in its youth apprenticeship program.⁵ Unfortunately, the current apprenticeship program lacks any focus on outreach or inclusion of youth with disabilities.⁶

Project SEARCH is one of the many successful work-based learning models that provide students with disabilities with on-site, work experiences within a major community employer. Research has found that the majority of Project SEARCH participants secured permanent jobs following their work-based learning experiences. Congress recognized the effectiveness of work-based learning by including the best practice as a required activity under the pre-employment transition services (Sec. 422) provision of the Workforce Innovation Opportunity Act (WIOA). Under WIOA, students with disabilities are required to receive work-based learning experiences through a 15 percent Vocational Rehabilitation (VR) program funding set aside.

It should be noted that work-based learning models must be a supplement to academic instruction and not supplant academics. It is essential that a continuum of support is available, from strong academics and work-based learning, to job placement, and job maintenance. Many individuals need continued supported employment services. Unfortunately, too often students with significant disabilities have little meaningful education and employment transition services, and there is a paucity of trained, competent job developers in many localities. Self-contained “life skills” classes with group sheltered-work type experiences lead to a life of no paid work or sheltered work at subminimum wage. Appropriate education with services and supports, and the utilization of the principles of Universal Design for Learning, work-based learning, supported employment, and the opportunity to access higher education instead lead to competitive, integrated employment.

Question 2: Given the requirement of VR agencies to serve transition-age individuals, the availability of Individualized Education Programs (IEP) and Section 504 plans in school settings,

² Predictors of Postschool Employment Outcomes for Young Adults with Severe Disabilities [research paper](#), 2015

³ Transitioning Youth With Intellectual and Other Developmental Disabilities: Predicting Community Employment Outcomes [report](#), 2015

⁴ What to Know about Work-Based Learning Experiences for Students and Youth with Disabilities [report](#), 2015

⁵ <https://youthbuild.workforcegps.org/resources/2016/02/26/14/20/Registered-Apprenticeship-Toolkit>;

⁶ <http://c-c-d.org/fichiers/CCD-Apprenticeship-Letter-11-17-17-FINAL.pdf>

and the availability of services and supports elsewhere available to youths, what should SSA's role be in assisting the transition of youths to adulthood?

SSA's role should be one of ensuring that youth, families and those who provide supports have accurate and easily-understandable information and that SSA's rules do not discourage work-based learning and other vocational preparation experiences while in school. It is also important that SSA coordinate with other agencies to ensure that such information is widely available to personnel in those agencies. It is not unusual for school personnel or vocational rehabilitation counselors to provide inaccurate or incomplete information to families and youth regarding social security-related information, work incentives, etc.

SSA should establish a data exchange with the Department of Education to ensure that all children receiving SSI have been identified and offered an evaluation for special education and other services through an Individualized Education Program (IEP) or 504 plan. Policies need to change so that SSI recipients may be referred to vocational rehabilitation and collaboration among ED and SSA in ensuring accurate, understandable information is important.

SSA should also inform youth approaching transition age, and their families and those who provide supports, about their upcoming redeterminations, adhere to the agency's duty to develop the record for such redeterminations, and carry out redeterminations and any appeals of them in a prompt and policy-compliant fashion.

Question 3: How might SSA better support other agencies' youth transition-related activities?

SSA can and should support the Department of Education in doing a better job of ensuring that youth SSI beneficiaries are prepared to transition from secondary school by providing data regarding which students are receiving SSI. As stated above, SSA should establish a data exchange with the Department of Education to ensure that all kids receiving SSI have at least been identified and offered an evaluation for special education and other services through an IEP or 504 plan. SSA can also provide its publications designed to assist youth receiving SSI and their families for the age 18-year-old redetermination and how work affects a young person's benefits both to the SSI beneficiary and local education agencies for distribution to SSI youth.

Question 4: Are there aspects of SSA's publications, mailings, and online information that SSA can improve to better support successful transitions to adulthood of youths receiving SSI?

SSA's new brochure for youth approaching the age-18 redetermination is a positive addition to SSA's publications because it informs youth of their rights and provides essential information that will help them prepare for the transition to adulthood. SSA should continue sending the brochure to youth, families and those who provide supports and ensure that its partners at the Department of Education are aware of the publication and share it when appropriate. SSA could do a better job of communicating with SSI youth in a variety of ways.

The brochure, like many SSA publications, is complex and difficult for many young people with disabilities to understand, particularly for youth with intellectual disabilities, so we recommend a few steps to improve the brochure to make it more accessible and engaging, consistent with principles of Universal Design for Learning. First, we recommend that SSA simplify the language in the brochure because some youth with disabilities have lower literacy levels than their peers. Second, we suggest that SSA put some of the information from the brochure in another format, such as video, to make it more accessible and engaging. Finally, we urge SSA to conduct research to evaluate the effectiveness of the brochure in terms of how well youth access, understand, and implement the information.

SSA should also evaluate all communications and publications targeted at youth to ensure that they are culturally and linguistically appropriate for the audience.⁷ Part of doing so is to ensure that every publication targeted at youth is evaluated by both SSI youth and their families prior to publication.

The redesigned brochure should be easy to find on the SSA website. NDSC recommends that SSA provide an easy-to-find, easy-to-access, dedicated resource page for youth receiving SSI to access relevant materials from SSA and to connect to other agencies. Examples of relevant resources include: the Red Book, “Resources To Assist Youth With the Transition To A Successful Adulthood” (<https://www.ssa.gov/redbook/eng/resources-youth.htm>); the brochure, “What You Need to Know About Your Supplemental Security Income (SSI) When You Turn 18” (<https://www.ssa.gov/ssi/spotlights/spot-disabled-youth.htm>); and the “Spotlight On SSI Benefits For Disabled Or Blind Youth In Foster Care” (<https://www.ssa.gov/ssi/spotlights/spot-disabled-youth.htm>).

SSA should maximize the accessibility of its content including for youth with low literacy, learning disabilities, and intellectual disability. The Cognitive and Learning Disabilities Accessibility Task Force of the World Wide Web Consortium (<https://www.w3.org/WAI/PF/cognitive-a11y-tf/>) is currently developing recommendations and, on a preliminary basis, recommends use of multi-modal content delivery including captioned video. More information is available at:

- <https://w3c.github.io/coga/gap-analysis/#solutions-for-multi-modal-content-delivery>
- <https://w3c.github.io/coga/issue-papers/multi-modal.html>

In addition, the availability of the WIPA and PABSS programs to assist young people with questions regarding work and transition should be highlighted on this page.

SSA should also provide more targeted information to youth, families, caregivers and higher education programs for students with ID about how work incentives can be used by students with ID in college.

⁷ See <https://content.iospress.com/articles/journal-of-vocational-rehabilitation/jvr821> for suggestions in this area.

Question 5: How can SSA improve its existing work incentive policies, such as the Student Earned Income Exclusion (SEIE) and Impairment-Related Work Expenses (IRWE), to better support and increase SSI youth engagement in work? Are there alternative models that SSA should consider to replace existing work incentives?

- **Codify current rules regarding continuing disability reviews (CDRs) for children and young adults.** We recommend that SSA not conduct CDRs or redeterminations for children engaged in transition-to-work activities and that the current mandatory SSI redetermination at age 18 be moved to age 22 to parallel the time frames under the Individuals with Disabilities Education Act (IDEA) and Social Security's Disabled Adult Child program.

Question 8: If SSA were to conduct a new demonstration project related to youth, which populations should SSA consider targeting, if any? How can SSA identify these populations? How many individuals enter these populations per year?

NDSC recommends that SSA develop a demonstration program to examine the impact that higher education has on the lives of individuals with ID who are recipients of SSI, in particular the impact on the outcome of competitive integrated employment.

The program should include collaboration with at a minimum the Office of Special Education Programs, Office of Postsecondary Education, the Rehabilitation Services Administration in the U.S. Department of Education, and the Centers for Medicare & Medicaid Services. Developing ways to blend and braid funding for students with ID for services and tuition should be a part of the project in order to reach the mutual goal of competitive integrated employment.

A lack of alignment between the Higher Education Act, IDEA and WIOA should be addressed in the demonstration program. While HEA specifies a preference for collaboration with, and the use of IDEA and vocational rehabilitation funds, in the TPSID grants, two recent Department of Education guidance documents create barriers for doing so. While the Preamble to the IDEA 2004 regulations clearly states that IDEA Part B funds may be used to support students with intellectual disabilities in postsecondary programs, more recent guidance severely limits doing so. (See OSERS' May 2017 *Transition Guide to Postsecondary Education and Employment for Students and Youth with Disabilities* which addresses the use of IDEA Part B funds to pay costs associated with providing FAPE to students with disabilities enrolled in postsecondary programs on page 3. <https://www2.ed.gov/about/offices/list/osers/transition/products/postsecondary-transition-guide-2017.pdf>)

Additionally, RSA TECHNICAL ASSISTANCE CIRCULAR RSA-TAC-17-01 DATE: August 17, 2017 has been interpreted by some states to disallow the use of WIOA Pre-Employment Services (Pre-ETS) funding for students in higher education programs for students with ID. The demonstration program should waive these prohibitions.

One of the aspects of the project should be to identify desired outcomes for these students. Receiving enough income from work to no longer be eligible for SSI or Medicaid is currently considered the ultimate outcome. For these students it may not be a realistic or desirable outcome, given the critical role of SSI/Medicaid in health care and in providing community based supports and services, such as employment and housing supports. Consideration should be given to the outcome of obtaining competitive, integrated employment in the community, even if the income is not sufficient to lose eligibility for services.

We also recommend that that any future SSA initiatives include higher education programs for students with ID as a means to improve employment outcomes.

Thank you for the opportunity to provide information regarding strategies to improve outcomes for youth SSI beneficiaries in adulthood. If you have any questions or would like further information, please contact Stephanie Smith Lee, NDSC Senior Policy Advisor, at stephaniesmithlee@gmail.com

Sincerely,



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Executive Director
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