



Commemorating 40 Years  
Of Disability Advocacy  
1973-2013

*Submitted via [www.ed.gov/PROMISE](http://www.ed.gov/PROMISE)*

March 17, 2013

PROMISE Program, a Joint Initiative of:  
U.S. Department of Education  
U.S. Department of Labor  
U.S. Department of Health and Human Services  
Social Security Administration

**Re: Request for comments on draft priority for the  
PROMISE Program**

To Whom It May Concern:

These comments are submitted by the co-chairs of the Social Security Task Force, the Education Task Force, and the Employment and Training Task Force of the Consortium for Citizens with Disabilities (CCD) in response to the “Public Input Notice,” (February 15, 2013, <http://www2.ed.gov/about/inits/ed/promise/promise-pin.pdf>). The Notice seeks comments from the public regarding the PROMISE Program’s draft priority regarding proposed requirements, definitions, and selection criteria for the PROMISE competition, for consideration as the final priority is developed for publication in a Notice Inviting Applications in the Federal Register later this spring.

CCD is a working coalition of national consumer, advocacy, provider, and professional organizations working together with and on behalf of the nearly 57 million children and adults with disabilities and their families living in the United States. The CCD Social Security Task Force focuses on disability policy issues in the Title II disability programs and the Supplemental Security Income (SSI) program. The Employment and Training Task Force works on issues relevant to the employment of people with disabilities, including proposed efforts by the Social Security Administration to support the employment of individuals receiving Social Security and SSI benefits, and the employment and training programs administered by the Department of Labor. The Education Task Force focuses on education policy and represents the nearly 6 million K-12 students attending our nation’s public schools.

**Request for Input on the Overview of Program section:**

SSI provides vital support for children with severe disabilities and their families. The extra expenses incurred and the income lost when a parent reduces his or her hours or leaves a job altogether to stay home to care for a child with a severe disability can be crushing. For many families with a child with a disability, the modest income support from SSI (on average, \$619 per month in 2012) means the difference between living above or below the poverty line, and

between being able to provide for their child with a disability and having to go without basic necessities.<sup>1</sup>

Families caring for children with disabilities face an array of expenses, such as: transportation to and from doctors' appointments and supportive services (especially in rural areas); specialized child care; adaptive equipment and reading aids; special diets and activities that help in overcoming or minimizing the effects of impairments; diapers for larger children and adolescents who are incontinent or not fully "potty-trained"; among others. Many of these expenses may not be covered by Medicaid or private insurance, forcing families to cover them out-of-pocket.

Research shows that families caring for children with disabilities are significantly more likely to experience material hardships due to economic insecurity. Families with a disabled child are twice as likely as other families with children to experience material hardships such as food insecurity (e.g., skipping meals because of lack of money, or running out of food), and housing and utility hardships (e.g., being unable to pay rent, or having utility service shut off)—even controlling for income, education, and other similar factors.<sup>2</sup>

Along with Medicaid and educational services provided by the IDEA, the income support from SSI plays a key part in making it possible for families to care for their children with disabilities at home instead of in costly institutions, and to meet their children's basic as well as special needs.

However, as discussed in detail in the PROMISE PIN, recent research documents significant challenges for youth with disabilities. They are less likely than other youth to attain a high school diploma, to obtain employment, or to enroll in post-secondary education. They also face higher rates of arrest, a higher rate of substance abuse and general disconnection. High school non-completers have a significantly higher rate of arrest than completers.<sup>3</sup> Also discussed in the PIN, research suggests a need for better coordination across agencies providing supportive and transition services to youth with disabilities. Moreover, modifications to SSI program rules—and to other programs administered by PROMISE partner agencies such as Vocational Rehabilitation—may facilitate improved employment and educational outcomes for youth with disabilities who receive SSI.

We support the stated goals of the PROMISE initiative:

- to increase access to supportive services for transition-age youth with disabilities;
- to strengthen coordination across agencies to improve postsecondary education and employment outcomes for youth with disabilities;
- to increase support to families of children with disabilities;
- to explore and test strategies for removing barriers to positive employment and

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<sup>1</sup> Shawn Fremstad and Rebecca Vallas, National Academy on Social Insurance, "Supplemental Security Income for Children with Disabilities." (November 20, 2012, Social Security Brief No. 40), available at <http://www.nasi.org/research/2012/supplemental-security-income-children-disabilities>.

<sup>2</sup> See, e.g., Susan Parish et al., 2008. "Material hardship in U.S. families raising children with disabilities." *Exceptional Children*, 75(1), at 71; and Material Hardship in U.S. Families Raising Children with Disabilities: Research Summary and Policy Implications, University of North Carolina, March 2009.

<sup>3</sup> Substance Use Among Young Adults With Disabilities, NLTS2, 2008.

- postsecondary education outcomes for youth with disabilities; and
- to build an evidence base regarding the effectiveness of potential interventions.

We appreciate the opportunity to comment on the PROMISE draft priority.

**Request for Input on the Eligibility Requirements section:**

Careful consideration must be made to ensure that “creaming” or the selection of “preferred” participants who may be more likely to succeed, including those who will receive intervention and those who will not, does not happen. The selection of participants should be held to similar criteria across all sites and include individuals from diverse backgrounds.

Use of terminology in the proposed PROMISE scope of “coordinated set of activities” is specific language used in the IDEA transition mandates which schools are required to provide to transition-aged youth already. Is the intent to further strengthen and clarify these services to ensure better outcomes? Further, the services highlighted (e.g. case management, benefits counseling, and work-based learning) are all potential transition services that should be readily available to all students and should be considered best practice for at-risk and disadvantaged youth including those eligible.

Individuals with the most significant disabilities who have been historically been classified as unable to achieve an employment outcome should be included in the project.

**Request for Input on the Priority section:**

The PIN enumerates four goals that the PROMISE model demonstration project (MDP) interventions should be designed to meet:

- increased educational attainment;
- improved rates of employment, wages/earnings, and job retention;
- increased total household income; and
- long-term reduction in SSI payments.

These four goals are indisputably important measures; however we urge that the final priority include additional goals regarding the health, well-being, and quality of life of participating youth (as included in the Youth Transition Demonstration Projects project design (“YTD”).<sup>4</sup>

Additionally, regarding the ages of eligible youth, the age range provided in the draft priority (14-16, with a request for input as to youth age 17) is extremely limited. Youth with disabilities face significant barriers and challenges well past age 16-17, as well as beyond the SSI age-18 redetermination. We urge that inclusion of older youth and young adults in PROMISE be

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<sup>4</sup> Rangarajan et al., The Social Security Administration’s Youth Transition Demonstration Projects: Evaluation Design Report, January 30, 2009, at 117.

considered.<sup>5</sup> Specifically, the Individuals with Disabilities Education Act (IDEA) allows eligibility thru age 21 [and beyond in certain states choosing to exceed federal law] for eligible students requiring special education services per their Individualized Education Program. We recommend expanding the age thru age 21 to ensure consistency with federal special education law.

**Request for Input on the Project Activities section:**

We support the requirement that PROMISE involve all the players in a student’s life during school and those who will be providing services through the transition period and into adulthood. This includes school personnel involved in the transition plan; vocational rehabilitation counselors, a representative from the adult Developmental Disabilities system, and family members. In addition, individuals who are experienced in job development need to be part of the process.

While in school, students need to be offered activities that will lead to integrated competitive employment such as job mentoring opportunities and internships in real integrated employment settings.

Individuals who are leading this transition process need to advise students and parents that employment is the desired outcome for transition youth with disabilities. A benefits specialist who can explain how this impacts public benefits needs also to be involved.

We would expand the list included in the PIN on (4) to consider for potential partners --that are not required but that applicants “may propose” such as: Employment Networks, employers or employer organizations, community colleges, institutions of higher education, work based learning programs, independent living centers, and agencies that administer or carry out adult education programs including literacy training, career and technical education programs, and maternal and child welfare programs.

**Request for Input on the Services and Supports section:**

We strongly support the wide array of services and supports enumerated in this section of the PIN. Case management services are critical for transition-age youth, as are benefits counseling, work-based learning experiences, and family education and support.

Regarding benefits counseling, it should be noted that the Work Incentives Planning and Assistance program (WIPA) has not as yet been reauthorized and is currently in jeopardy if reauthorization and funding to appropriate levels does not occur soon. Adequate benefits counseling is critical to ensuring youth and their families are informed about SSI work incentives, earnings rules, asset limits, etc. as well as the interaction between SSI, Medicaid, and other programs—especially if there are waivers in place.

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<sup>5</sup> As an example, the YTD project design includes young adults up to age 25, in recognition of the barriers and challenges faced by older youth and young adults. See id at 35.

The PROMISE PIN explicitly names “parent training and information” as a required service/support that MDPs must provide. As parents typically serve as the representative payees for their minor children, and for adult children in their care (as needed, depending on their child’s level of functioning and self-care), we urge that benefits counseling be explicitly included in the parent training and information service component. An addition to the existing scope of work for the state-based, federally funded Parent Training and Information Centers under IDEA should also be considered as the network currently exists in each state and could provide additional information and benefit to families and individuals.

We also strongly support the inclusion of many of the additional services listed on pp. 25-27 of the PIN, most especially:

- independent living activities, such as assistance in locating and obtaining housing, health providers, and personal attendant services; transportation training and subsidies; childcare services; and other community supports; and
- health and behavioral management and wellness services, including transition to adult services.

Regarding the request for input on what programs and strategies have shown potential for improving key outcomes for child SSI recipients and their families, we urge consideration of the Social Security Administration’s Youth Transition Demonstration Projects.

### **Request for Input on the Participant Outreach and Recruitment section:**

We encourage consideration of additional outreach activities targeting state and local disability advocacy and other groups that work with and are likely to be a good source of PROMISE-eligible youth with disabilities (e.g., state and local advocacy organizations, state and local service providers, state and local legal services organizations, state Protection and Advocacy organizations).

We strongly support the PIN’s explicit mention of the need for all outreach and recruitment materials to be accessible for individuals with disabilities. It is equally important that all written materials be presented in the family’s preferred language, using understandable, jargon-free language approximating a 6<sup>th</sup> to 8<sup>th</sup> grade reading level.

As an additional note, the YTD project in West Virginia (West Virginia Youth Works) observed that telephone- and mailing-only outreach was insufficient to achieve enrollment and follow-through by youth participants, and that in-person outreach made a critical difference in maintaining interest and participation by youth participants.<sup>6</sup>

### **Request for Input on the Technical Assistance and Training section:**

High-quality, ongoing technical assistance and effective training of all MDP partners and staff—

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<sup>6</sup> Mathematica Policy Research, The Social Security Administration’s Youth Transition Demonstration Projects: Interim Report on West Virginia Youth Works, December 2012.

especially on SSI program rules and any waivers included in the MDP design—will be a critical component of MDP design. We urge that the quality and comprehensiveness of training and technical assistance be closely monitored by the federal PROMISE partners, and that involvement by the PROMISE federal agency partners be considered to ensure consistency and quality.

**Request for Input on the Performance Measures section:**

The six performance measures enumerated in this section of the PIN are indisputably important; however we urge that the final priority include additional measures regarding the health, well-being, and quality of life of participating youth (as included in the Youth Transition Demonstration Projects project design (“YTD”)<sup>7</sup> as well as enrollment in supportive and health services, training programs, and other beneficial services.

**Request for Input on the Data Collection section:**

In addition to the quantitative data described in this section of the PIN, we urge that the MDPs collect qualitative data through interviews with youth participants and their families. Qualitative data of this sort is tremendously beneficial to understanding the experience of transition-age youth with disabilities (or any individuals with disabilities receiving benefits from Social Security), yet is rarely collected. The PROMISE MDPs should be strongly encouraged (if not required) to interview youth who receive SSI in both treatment and control groups.

**Request for Input on the Application Requirements section:**

An additional ongoing project to add to the list of federally funded programs for potential collaboration, sharing of information, and technical assistance [listed in part (c) of this section] is the Youth Transition Demonstration Projects (YTD):

<http://www.ssa.gov/disabilityresearch/youth.htm>

<http://www.mathematica-mpr.com/disability/ytd.asp>

**Request for Input on the Waivers section:**

The SSI program as currently structured provides considerable work incentives, especially for youth who are able (or want to try) to do some work. Under current program rules, the first \$85 of earnings each month is not counted against the monthly SSI benefit. After that, only half of earnings are counted against the benefit. This means an SSI recipient, child or adult, always receives more income if she works than from receiving SSI alone—the amount she receives from earnings plus SSI will be greater than the amount of just the monthly benefit. For recipients under age 22, the Student Earned Income Exclusion (SEIE) is even more generous, allowing SSI recipients under age 22 who are regularly attending school to exclude all earnings up to \$1,730

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<sup>7</sup> Rangarajan et al., The Social Security Administration’s Youth Transition Demonstration Projects: Evaluation Design Report, January 30, 2009, at 117.

per month, up to a yearly maximum of \$6,960 (for 2013). (The purpose of the SEIE is to help youth access internships and the other early work experiences that are so important to preparing for adult employment.)<sup>8</sup> Additionally, in most states, Medicaid coverage is continued if the child ceases to receive the SSI cash benefit due to earned income, so long as certain criteria are met.

An additional work incentive is found in the Section 301 program, which enables teenagers to continue receiving SSI benefits while they finish school and transition into special state-run vocational rehabilitation programs. This encourages them to complete school and enables them to begin working, build skills, and develop a connection to the workforce while transitioning off of SSI assistance.<sup>9</sup>

However, SSI's work incentives could be further strengthened to more effectively support transition-age youth in post-secondary education and early work experiences, as well as to encourage savings. SSA's ongoing Youth Transition Demonstration Projects (YTD) offer a rich menu of options for waiving SSI program rules to enhance SSI's work and education supports for youth receiving benefits:

- 1) ***Student Earned Income Exclusion (SEIE)***: Normally the SEIE applies only to students who are age 21 or younger, and is subject to monthly as well as yearly caps as described above. Through a waiver, the SEIE should be applied to all youth in PROMISE treatment groups, regardless of age and without monthly or yearly caps, to further encourage and support early work experiences and earnings.
- 2) ***Earned Income Exclusion (EIE)***: Normally, SSA disregards the first \$65 plus half of all remaining earnings when computing countable income to determine an SSI recipient's monthly benefit. (The EIE is applied to earnings after applying all other applicable exclusions, including the General Income Exclusion of \$20 per month and the SEIE, described above). Through a waiver, the EIE should be enhanced for PROMISE youth to exclude \$65 plus three-fourths of any additional earnings, to further support and encourage earnings from work.
- 3) ***Plan for Achieving Self-Support (PASS)***: Under PASS, qualifying SSI recipients are permitted to save money (other than SSI funds) to pay for items or services needed to achieve a specific employment or self-employment goal.<sup>10</sup> SSI program rules do not include post-secondary education as a permissible goal for purposes of PASS. Through a waiver, post-secondary education should be included as an eligible PASS goal for PROMISE youth, to further encourage and support post-secondary education.
- 4) ***Individual Development Accounts (IDA)***: IDAs are "trust-like" savings accounts. For each dollar of earnings an account holder deposits, a participating nonprofit organization can set aside a matching contribution from 50 cents to four dollars. (The average matching contribution is one dollar). IDA programs involving federal funds (such as SSI benefits) also incur a federal match. IDA funds are restricted to specific purposes, including purchase of a

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<sup>8</sup> For more on the Student Earned Income Exclusion, see Social Security Administration, "Spotlight on the Student Earned Income Exclusion," updated February 2013, available at <http://www.socialsecurity.gov/ssi/spotlights/spot-student-earned-income.htm>.

<sup>9</sup> The Section 301 Program provides for continued payment of SSI benefits for individuals in a vocational rehabilitation or similar program. See Social Security Administration, "SSI and SSDI Employment Supports," *The Red Book 2013*, available at <http://www.ssa.gov/redbook/eng/main.htm>.

<sup>10</sup> For more information on PASS, see Social Security Administration, Plans to Achieve Self-Support, available at <http://www.socialsecurity.gov/disabilityresearch/wi/pass.htm> (accessed March 11, 2013).

home, paying for post-secondary education, and starting a small business. Under SSI program rules, Social Security counts deposits to IDAs by the account holder as countable income, but disregards matching deposits, IDA account balances, and any interest earned by the account in determining SSI eligibility for an individual with a federally funded IDA. Under a waiver, PROMISE youth should be permitted to deposit funds into an IDA without penalty to their monthly SSI benefit, and this and the normal SSI disregards should apply to all IDAs including ones that do not involve federal funds and thus which may be used for other purposes than those enumerated above. This waiver would further encourage savings by SSI youth.

- 5) **Continuing Disability Reviews (CDR)**: Normally when a child or adult is reviewed under a CDR and found no longer eligible for continued SSI benefits, the individual's benefits cease (subject to payment continuation in conjunction with an appeal). Under a waiver, SSA should either not conduct CDRs for PROMISE youth, or alternatively should permit PROMISE youth to continue receiving benefits even if found no longer eligible via a CDR. To the extent that PROMISE serves youth after age 18 (see page 3 of these comments), under a waiver SSA should move redeterminations for PROMISE youth to age 22 to parallel the timeframes in IDEA and the Social Security / Disabled Adult Child programs. Current regulations already provide that benefits will continue for students age 18 to 21 if they receive services under an individualized education plan, even if they recover medically or their disability has been determined to have ended.

As a general matter, we urge that no participants or families be negatively affected through participation in the project in any way. Pursuant to the Social Security Administration's demonstration authority, no PROMISE participant should have his or her SSI benefits reduced due to participation in the program:

“(A) the Commissioner is not authorized to carry out any project that would result in a substantial reduction in any individual's total income and resources as a result of his or her participation in the project;” (42 U.S.C. 1310).

#### **Request for Input on the Awards section:**

Given that the purpose of PROMISE is to explore and evaluate potential interventions to improve educational, employment and other outcomes for youth receiving SSI, it may be premature to employ an outcome-based payment structure for this initiative.

#### **Request for Input on the Selection Criteria section:**

We strongly support the consideration of the criterion set forth in D (ii) of this section: “the extent to which the proposed project seeks, encourages and includes feedback from participating child SSI recipients...” and described above in our comments on the Performance Measures section of the draft priority, we urge that MDPs be strongly encouraged if not required to conduct interviews with participating youth and their families to obtain valuable qualitative data on the usefulness and appropriateness of MDP interventions.



Sincerely,

Alicia Epstein, NISH  
Co-Chair, CCD Employment and Training Task Force

Susan Goodman, National Down Syndrome Congress  
Co-Chair, CCD Employment and Training Task Force

Peggy Hathaway, National Association of Councils on Developmental Disabilities  
Co-Chair, CCD Employment and Training Task Force

Laura Kaloi, National Center for Learning Disabilities (NCLD)  
Co-Chair, CCD Education Task Force

Jeanne Morin, National Association of Disability Representatives  
Co-Chair, CCD Social Security Task Force

Katy Neas, Easter Seals (ES)  
Co-Chair, CCD Education Task Force

Paul Seifert, Goodwill Industries  
Co-Chair, CCD Employment and Training Task Force

Cindy Smith, National Disability Rights Network  
Co-Chair, CCD Education Task Force

T.J. Sutcliffe, The Arc of the United States  
Co-Chair, CCD Social Security Task Force

Rebecca Vallas, Community Legal Services  
Co-Chair, CCD Social Security Task Force

Ethel Zelenske, National Organization of Social Security Claimants' Representatives  
Co-Chair, CCD Social Security Task Force