

PROMOTING READINESS OF MINORS IN SUPPLEMENTAL SECURITY INCOME (PROMISE)

ADVOCACY GROUP INPUT MEETING NOTES

NOVEMBER 8, 2012

Panelists include representatives from the following organizations: The Arc of the United States, Autistic Self Advocacy Network, Collaboration to Promote Self Determination, Council for Exceptional Children, Institute for Educational Leadership, National Council on Independent Living, National Down Syndrome Society, and National Federation of the Blind.

WELCOME AND INTRODUCTIONS

Michael Yudin, OSERS Acting Assistant Secretary: This is an important conversation for us to have-- PROMISE gets to the core of a critical issue—improving outcomes for children and youth on Supplemental Security Income (SSI). Providing parents and families with support is particularly important to this effort. We’re here today to get input from you on how to make this work because this represents great opportunity to truly make a difference in the lives of these children and their families.

PROMISE OVERVIEW

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The topic of transition is incredibly complex, and then adding in SSI makes it more complex. PROMISE is a multi-agency pilot model demonstration program led by a consortium of federal government agencies, including ED, SSA, Labor, and HHS. The goal is to test interventions that improve health, education, and post-school outcomes for children who receive SSI and their families. It seeks to improve the provision and integration of services and supports that will help children achieve better education and post-school outcomes (e.g., completion of post-secondary education, employment)—resulting in less long-term reliance on SSI.

PROMISE was designed with a number of distinguishing features:

1. Collaboration of four federal agencies (Health and Human Services, Social Security Administration, Department of Labor, Department of Education).
2. Targeting support to youth as well as their families. This will involve the participation of programs that may not typically focus on youth. We are looking at having a planning year for these projects. It’s complex enough that we want to work closely with the projects following the competition process to make sure the structures are in place to be successful.
3. We’re thinking about waivers allowing flexible access to services for program participants.
4. We are also looking at incentives or outcome-based payments, including pay-for-success arrangements.
5. We want a rigorous evaluation design that will guide implementation and the gathering of evidence, as well as validate incentive payments.

Thus far, we’ve had technical advisory panels looking at evaluation design and incentive payments, as well as expert panels talking about what those interventions and services might look like for youth and families. Input has included experts from within the federal government, as well as various stakeholders,

including parents, youth, vocational rehabilitation (VR) and special education experts from the field. Input was gathered at this year's Annual Capacity Building Institute in Charlotte, NC, as well as the National Transition Conference, which was also held earlier this year in DC. In June, we gathered input from philanthropic foundations on how to develop and implement PROMISE. Input from these various sessions, along with a blog, are available on the PROMISE website: www.ed.gov/promise. Finally, we are also having a literature review done by AIR to see what effective or impactful things might be used within PROMISE.

By end of FY 2013, we want to award 3-5 grants with a budget of \$30 million. Applicants will be states. PROMISE grantees will seek to coordinate/collaborate with non-governmental organizations, including advocacy groups; efforts should be coordinated through the states.

DISCUSSION

A federal government employee: We have not made any decisions about who the lead partner will be. We want partnerships among state agencies, particularly because we're targeting both youth and families. We're just trying to decide if we want to require certain agencies to be in the mix.

A panelist: Can only state agencies head projects, or are state entities eligible too? For example, a workforce council, health departments, or independent living councils. The panelist cited Medicaid Infrastructure grants, where both state agencies and entities were allowed. Entities are still under the purview of the governor.

A federal government employee: We haven't faced that squarely. We need a lead agency that can marshal the resources across agencies in the project. We want to go after resources that are already out there. This is something we can discuss. It would be helpful for us to have examples of state entities.

A panelist: Is there a match requirement?

A federal government employee: No.

A panelist: Look at HUD. Panelist stated that he/she can supply a useful link. It provides language on roles and responsibilities. This was in the application—it required agencies to do a preliminary take of roles and responsibilities. It is helpful from an advocacy perspective for states to start that conversation as part of the application process.

A panelist: Collaboration is one thing—will this proposal permit the braiding and blending of funding?

A federal government employee: We're looking at input on the kinds of waivers to make that possible. We don't have legislative authority beyond what's in existing waiver authority for blending. One way to get blending is to use the grant money to do things that you can't do in other programs. We want to

leverage existing programs, understanding that they're not all complementary. We are looking at innovative ways for states to collaborate and we would encourage ways that states might do braiding and blending of funding at the state level. We will look for innovations to do so at the state level.

A federal government employee: There are ongoing discussions about services—what is required versus what is suggested—we're looking at evidence around those services. We would like input on that. We're also looking at data collection and evaluation requirements—administrative data as well as other ways to collect data—and partners: what's the mix of required versus suggested partners that states select themselves.

A federal government employee: We should have more detail by end of year. We are posting a Public Input Notice (PIN) by end of year offering what we're thinking about PROMISE. Advocates will have an opportunity to see the PIN. It will be on the PROMISE website.

REQUIRED PARTNERS:

A federal government employee: We want input on the partners who should be at the table to pull off the goal of this project.

A federal government employee: Medicaid, State Education Agencies, and VR agencies should be required partners. There may also be a role for the One Stops, at the very least as an optional partner. Much of the population falls within the developmental disability (DD) or mental health categories. In most states, there is a designated agency responsible for DD that receives Medicaid funding. In a few states, that entity shares responsibility for DD and mental health, or DD and physical disabilities. The populations are primarily in the DD and mental health sectors, so it might make sense to call out the state agency(ies) with responsibility over DD and over mental health. It can't just be the State Medicare Director.

A panelist: I don't want to narrow out folks that would be missed in other groups. Articulate that in a way that all disability groups are represented. Certainly groups like DD and mental health can be represented in the way the previous speaker said, but we don't want to leave out other populations.

A federal government employee: Agreed.

A panelist: Regarding One Stop centers or systems—it would be interesting to think about ways to encourage applicants to consider new and meaningful roles for the One Stops. I realize that that's not the focus of this, but it can provide opportunities for states to provide stronger, more meaningful partnerships with One Stops which opens up more resources for youth with disabilities. It might not be a mandated partner role, but it's something to consider in the application as a whole.

A federal government employee: That could be good in the consideration of involving parents.

A panelist: You should look at financial literature and small business start-ups to have the flexibility. Primarily asset-building.

A panelist: Include organizations run by people with disabilities, including self-advocacy and independent living centers. Also think about higher education—like getting community colleges or universities involved—and PTI Centers.

A panelist: You should consider Workforce and Employment networks.

A federal government employee: What services and supports do youth in high school who are receiving SSI need in order to improve their employment and educational outcomes?

A panelist: We don't really prepare students in any meaningful way to navigate service provision and legal rights after they leave school. They're used to entitlements under IDEA, with entities that provide those. After leaving school, the responsibility is on the youth with some support from family. So heavy emphasis on self-advocacy and self-direction would be beneficial, so we're not just pushing students along in IDEA entitlement and into Medicaid entitlement. We want them to operate within scope of VR, ADA, 504, employment, and higher education context.

A panelist: They need benefits planning. Also, kids with disabilities get less vocational exposure than nondisabled peers.

A panelist: Benefit counseling is necessary for youth and their families.

A federal government employee: Benefits planning is vital. But we need to move the conversation into a broader topic.

A panelist: Transition planning should begin much earlier than it currently does. Perhaps in the application, we can emphasize that point so that we're not just talking about the last year or last 2 years of high school. Ideally starting with 14 year olds.

A panelist: We need parent and teacher expectations to be higher, and for youth to have early work experiences. From a transition perspective, we need to focus on early work experience or mentorship programs with businesses in their communities.

A federal government employee: States actively engaged in converting systems to outcomes-based (competitive) employment or supported employment are meeting resistance from families who maintain that sheltered workshops are best option for their children. This comes from fear and a lack of information. Any project in PROMISE should take into account that kind of mentality—that sheltered workshops are really a service. They need to be educated that sheltered workshops are not where people should be at forever, and that there are other opportunities out there. There was a demonstration program looking at a very difficult population with fundamentally the same goal—reducing the number of people with chronic illness going on disability insurance program. It offered a limited scope of employment navigator services and health care benefits to participants prior to applying for SSI/SSDI. It might be interesting to see if there is a way to replicate that and to get around the parents' reality, where it's often difficult to access those types of services.

A federal government employee: What are the main barriers preventing states from effectively providing youth with the services they need to be successful?

A federal government employee: Where would waivers make sense?

A panelist: The bigger question concerns the decades of mythology. Particularly for students with significant or multiple disabilities, the folklore is that you don't want your kid to work, they'll lose their benefits, they can't live independently. It's a persisting mindset that is a real problem. It exists everywhere in the country, this terrible mythology. People don't understand the Ticket or the Medicaid buy-in. So parents say their kids will work, but not more than a certain amount, and the discussion ends.

A panelist: Advocates saw that in regard to a sheltered workshop. A family placed a child there even after being successful in community-based employment. They were worried about the earnings being too high and losing benefits. This reinforces the need for benefits planning.

A panelist: There is no entity at the local level with responsibility for postsecondary transition. For a student totally unprepared by an LEA to move into employment or education, the entity he or she must deal with then is VR. There is no single entity that says that this person should be going on to employment or higher education.

A federal government employee: If that's a gap, then we need to address that in PROMISE. We've been hearing that parental expectations are something that we need to address. That is an objective that our projects must tackle.

A federal government employee: Postsecondary education needs to be at the table.

A panelist: Parents and schools must have high expectations for youth. Self-advocacy and related skills are necessary. Issues such as disability history, disability rights, disability advocacy should be addressed because these help teach parents and educators.

A panelist: Expectations for parents are often set by educators. So parents need to be educated early about high expectations, options, and to believe in transition.

A panelist: There needs to be an innovation/intervention with the children. Use of organized sport can be a convening mechanism that fosters the learning of developmental skills that nondisabled are getting. The parents are brought into this, as well, and are active and engaged. They advocate and share resources. Sport brings to the forefront responsibility, goal setting, and high expectations. We need to think outside the box a little bit about how to effect change through this program.

A panelist: The need for some kind of dedicated case management is interesting. Educators have no incentive to get kids off SSI. If we could introduce some kind of shared outcomes metric or dedicated case management, so entities are held accountable for what happens after a child leaves school—that

would be intriguing. It also works for helping VR, and moving the opposite direction. But we need to focus on the movement from school districts to adult VR services.

A federal government employee: This speaks to the previous point about debunking the mythology. We should look at results-driven accountability and apply that to case management and responsibility for outcomes. The main point is how to change these expectations.

A panelist: I am questioning who has the responsibility for children that moves beyond the exit from school. We need unified case management that transitions with the children. With regard to parents, at some point we need to be working with parents to have high expectations both in terms of outcomes and service provision.

A federal government employee: Maybe we want to make it a requirement that grantees tell us how they're going to tackle that problem, particularly parental expectations. Parent need to be the ultimate advocate/case manager for children. These are low-income parents.

A panelist: PTIs are a vehicle for that.

A federal government employee: Looking at improving outcomes for families and youth, are there promising programs or practices in this domain that you would like us to be aware of?

A panelist: CEC has a division focusing on transition to career. They have developed 150 tips for successful transitions. Part of this focuses on the idea of interagency collaboration, and gives examples where this is working well and what that collaboration looks like.

A panelist: The Arc is completing a 3-year grant looking at transition from school to adult life (not employment focused, but broader). Grant officers are finalizing those examples, and we can share that work when it is complete.

A federal government employee: Yes, we want to provide resources that are currently out there to applicants.

A panelist: You should work with the NGA, especially Governor Markell, to gain assistance in working with the states.

A federal government employee: Perhaps take a look at what Maryland does. It can be adapted—look at the blending and braiding resources. It's a creative way for blending resources and collaborating expertise to push for more competitive employment opportunities for people with disabilities. It's an effective example of these things.

A federal government employee: In looking at transition age population on SSI, we know that there are many kids out there that have same diagnosis/same environment/etc., but they're not on SSI. They're working. But we don't know a lot about those kids. We're trying to identify what to do for those that aren't making it, but we need to figure out what's happening with those folks who are making it. We

don't really know what that looks like. All we know are our own interventions. We don't look at those that don't come into our system. PROMISE could help us do some of that.

A federal government employee: how would states even target them? What do they look like?

A federal government employee: There are two types of people. There are young people that were on SSI as kids and for whatever reason were able to get and stay off. We know a bit about them and need to dive deeper. And then there are some that have significant disabilities that never had to go on because they were able to get a good education and job. Those numbers are not large but represent levels success that we need to better understand if we are going to grow it.

A federal government employee: It would be good for us to understand.

A federal government employee: The point is that it is not just services, and if that is what we continue to just focus on, we will miss the entire game.

A federal government employee: We have to look at points in that family's situation where they make one choice over another, and we need to understand why those choices were made. Those choices have huge impact, and we just don't know much about that.

A panelist: It is important to go beyond services and supports. One thing we have the ability to track and measure is setting. ED has good info on what percentage of time is spent in general education settings. This is related to post-school outcomes. Setting is a way to operationalize the higher expectations issue. Students with disabilities in general education settings have higher expectations.

A panelist: With regard to partnerships, like the TA&D Network—they are very useful, especially the Secondary Transition TA Center. This project should use these resources.