



Maryland Developmental
Disabilities Council
EMPOWERMENT • OPPORTUNITY • INCLUSION



Maryland Center for Developmental Disabilities
at Kennedy Krieger Institute
Building Partnerships. Changing Lives.



August 9, 2017

via email

TO: Administration for Community Living

FR: Brian Cox, Executive Director and Eric Cole, Chairperson, Maryland Developmental Disabilities Council
Chris Smith, PhD, Director, Maryland Center for Developmental Disabilities
Meghan Marsh, Interim Executive Director, Disability Rights Maryland

RE: Proposed *Partnerships for Innovation, Inclusion and Independence* grant program

The Maryland Developmental Disabilities Council, Maryland Center for Developmental Disabilities and Disability Rights Maryland, which comprise the DD Network in Maryland, offer the following comments in response to the proposed *Partnerships for Innovation, Inclusion and Independence (P3I)* program. Our three entities have a long history of working effectively together in the unique ways articulated in the Developmental Disabilities Assistance and Bill of Rights Act (DD Act) and it is from this perspective that we offer our feedback. Thank you for the opportunity.

The Maryland Developmental Disabilities Council, Maryland Center for Developmental Disabilities and Disability Rights Maryland strongly oppose the proposed *Partnerships for Innovation, Inclusion and Independence* grant program.

Originally authorized in 1963 and last reauthorized in 2000, the DD Act established a set of programs to improve the lives of people with developmental disabilities (DD), to protect their civil and human rights, and to promote their maximum potential through increased independence, productivity, and integration into the community.¹ **Simply put – we think the DD Act got it right when it established Councils, UCEDDs and P & As with distinct, inter-related roles.** There is no evidence to suggest that the P3I program would more effectively promote evidence-based approaches, efficiencies, and provide a more cohesive approach to disability partnerships, as stated in the budget language.

Instead, the Maryland DD Network believes restructuring the activities carried out by the State Councils on Developmental Disabilities, Independent Living and Traumatic Brain Injury programs into a single state grant program will have a significant, lasting detrimental impact on the people with disabilities served by the three entities as well as the array of critical service systems we now help build capacity. **A plan predicated mainly on cost savings, as the P3I appears to be, is doomed to fail those it claims to better serve.**

Research & Analysis

The National Council on Disability (NCD), an *independent* federal agency making recommendations to the President and Congress to enhance the quality of life for all Americans with disabilities and their families, conducted a year-long study of the DD Act programs, culminating in a February 2011 report

entitled, *Rising Expectations: The Developmental Disabilities Act Revisited*. NCD's key findings and recommendations included the following, which are pertinent to the establishment of the P3I program.

Findings included (emphasis added):

- The DD Act, in conjunction with self-advocates, families, other advocacy groups, state and local governments, and other stakeholders, has changed the way people with DD live. In many ways, **it has been a remarkable change.**
- The DD Act programs have a **relatively low level of funding to address a relatively broad mandate** for a vulnerable population. In 2009, Congress appropriated \$160 million to the DD Act. Adjusted for inflation, this appropriation has remained at the same level for the past 20 years.

Recommendations included (emphasis added):

3.1 Congress should reaffirm the critical role played by the DD Councils in promoting the independence, productivity, and community integration of individuals with DD **by raising the annual appropriations for DD Councils** in order to improve their capacity for systems advocacy and demonstration activities.

The P3I proposal and concurrent \$57M cut are in direct conflict with the findings and recommendations of NCD, a non-partisan entity with deep knowledge about how best to address the needs of individuals with disabilities.

As far back as 1996, the concept of expanding the mandated focus of Developmental Disabilities Councils to include all disabilities was considered, analyzed – and rejected – through two Projects of National Significance grants. The Maryland DD Council was awarded one of those grants to study the impact and implications.ⁱⁱ The study included over 30 key stakeholder interviews with advocacy, service provider, and state agency organizations, as well as over 200 interviews with people with disabilities, representing current and potential Council constituencies. The study concluded that, “the Maryland Council is now considered effective in large part because of its state-of-the-art knowledge of policy, practice, and the support needs of its current constituency.” Furthermore, the study found that **“the Council is widely seen as effective because it is focused and thorough. Many stakeholders representing the potential expanded constituency shared the concern that an expansion would dilute this focused, thorough approach and analysis.”**

We believe this reasoning and justification still holds true today and provides more evidence that the role of DD Councils should not be diminished or changed as proposed through P3I.

The overview of the Administration's proposal states that the new cross-disability state councils established under the P3I program will place “greater emphasis on supporting delivery of services that help to achieve independence, productivity, integration, self-determination and inclusion in the community.” That is already at the core of what DD Councils do – and do most effectively alongside the P & A and UCEDD – and no greater emphasis is possible. **Rather, the P3I program with less than half the current funding will have the opposite effect by diminishing the ability to accomplish this, thereby producing far fewer outcomes and less measurable impact.**

Specialization is crucial to address the priority needs of the populations the DD Councils, State Independent Living Councils (SILC) and TBI programs focus on. While there are certainly shared issues, we already have the relationships in place to collaborate when that makes sense. DD Councils have a long history of collaborating with other organizations to accomplish mutual goals. However, the developmental disabilities system itself is very complex with endless issues to impact and improve, necessitating the specialized attention envisioned in the DD Act.

Although we do not support the consolidation plan, we offer the following feedback on the questions posed by the Administration on Community Living.

ACL QUESTIONS:

i. What single feature or function of your Council drives the purpose of your current Council, and if lost negatively impacts the purpose?

There is not one single feature or function that if lost would negatively impact the purpose of the DD Councils – there are many inter-related functions that were well conceived through the DD Act that have proven to be essential. DD Councils:

- Support people with developmental disabilities and their family members to develop self-advocacy and leadership skills to affect change in their own lives and the lives of others. *Through funding and support, Councils ensure that people with significant disabilities and their family members truly are empowered to “be at the table,” shaping public policy and services and supports as the DD Act envisioned.*
- Educate and inform policymakers about issues of importance to people with developmental disabilities and their families. *Councils are a unique non-partisan, conflict-free voice that the Governor’s office, legislators, and state officials rely on. The Maryland DD Council has been referred to more than once as Switzerland.*
- Advocate for policies, practices, laws, and services that support people with developmental disabilities to exercise control over their lives, reach their full potential, and lead productive, meaningful lives. *Councils function as catalysts, facilitators and leaders to engage diverse stakeholders in solving complex problems.*
- Design and fund initiatives that increase community inclusion, improve services and supports, and increase opportunities for people with developmental disabilities to pursue their hopes, dreams, and aspirations. *Through comprehensive analysis and strategic partnerships, Councils utilize limited funding to invest in initiatives to bring about lasting change. Funding and public policy goals are linked. In total, DD Councils throughout the nation leveraged over \$100 million each year over the past five years.ⁱⁱⁱ*
- Promote innovative approaches to supporting people to live, learn, work, and enjoy community life. *Councils support best and promising practices and then work to replicate and sustain successes to expand the benefit. For example, the MD DD Council funded the first family support services and supported employment for people with DD in the state many years ago. This helped establish the foundation upon which the current services were built – all without additional Council funding.*

- Advocate for the elimination of barriers that create separation and segregation and limit opportunities for full inclusion and community participation. *The Councils are essential partners with the UCEDDs and P & As in these activities with each of us contributing unique roles as outlined in the DD Act. We act in ways the DD Act envisioned.*

A unique over-arching feature of the DD Councils is the quasi-governmental status, located within state government while being ensured independence on issues related to advocacy, capacity building, and systemic change activities, budget, personnel, and State plan development and implementation.^{iv} This makes it possible for the DD Councils to represent their consistency while leveraging connections and opportunities made possible by this unique position. And when necessary, serving as a bridge between the community and government.

ii. Each current council represents and made up of people with different significant developmental, intellectual, physical and other disabilities. How can this representational role be incorporated in PIII?

One of the things that make DD Councils effective – and a model for other councils and commissions – is the high percentage of members with disabilities and the diversity of membership working collaboratively. It is also important that family members serve to represent children with disabilities. While it is essential that the majority of Council members – and its leadership – are people with disabilities, we have consistently found that the DD Council’s work is significantly enhanced by also having key state agency, community organization and sister agency representatives. This ensures that analyses, strategies and activities benefit from diverse real-world perspectives that enhance the quality and sustainability of the outcomes achieved by the Council. Citizens with disabilities and policymakers serving together – this must not be lost.

If the P3I program is implemented, we recommend that the new council structure ensure people with developmental (including ID), physical disabilities, TBI, and other covered disabilities – and their family members – represent at least 60% of the membership. We also recommend that key state agencies, community organizations and other entities are included, as currently required by the DD Act. The memberships must also be representative of the state (geographic, cultural, etc.).

We stress that the expanded P3I focus poses a logistical nightmare detrimental to efficient functioning. A Council that is too large will not function well (e.g., allowing for meaningful participation) and will be too costly given projected resources (e.g., transportation for members with disabilities). Relative to DD Councils and SILCs, the P3I Council would need to expand to include adequate and balanced representation from all disability groups. For example, the MD DD Council has a member who represents the DD service system. This is a critical partner to effect change in that system. Adding organizational representatives of the TBI and physical disability systems, in addition to individuals, would expand membership significantly.

The DD system is complex and focusing our membership on its array of challenges and opportunities requires skill, time, and support given that our members have different levels of understanding, experience, and learning styles. We work to ensure that all members, including those with intellectual disabilities, are meaningfully engaged. The DD Act rightly set out to ensure that people with the most significant disabilities have a voice. There is widespread concern in the DD community in Maryland that this will be lost as the P3I dilutes what is now functional through the DD Council.

iii. What are the challenges that can be addressed?

We do not believe the P3I structure will aid current challenges; rather, we believe it will exacerbate them leading to a far less effective council. Under the DD Act, DD Councils are charged with a comprehensive review and analysis of all pertinent state service systems to identify strengths, needs, and opportunities for improvement *relative to the needs of people with developmental disabilities and their families*. This is based on an objective analysis but also on extensive input from people with developmental disabilities, their families and allies throughout the state. With a lifespan focus, tremendous unmet need and limited funding, DD Councils work thoughtfully and strategically to set priorities. A P3I Council with a broadly expanded constituency and less than half the current funding will be impaired in its ability to set and act on priorities in ways that will have a deep and lasting impact.

Additionally, DD Council operations have been negatively impacted by flat federal funding. The Maryland DD Council has received the same amount of federal funding since 2002. During that same period, operational costs have inevitably increased while expectations and accountability have increased. The MD DD Council has dealt with this responsibly through cost cutting and priority setting but further cuts that will accompany the establishment of the P3I Council will result in far fewer staff resources and grant funds to impact the advocacy, capacity building and systems change, which the P3I Council is ostensibly designed to continue *and* improve. Consolidation will not solve DD Council challenges – it will only transfer them to the P3I Council and they will worsen.

iv. What requirements are important for Board/Governance and Representation as well as Appointment Process?

If a P3I Council is formed, we recommend the following based on what has helped the Maryland DD Council function effectively while meeting the letter and spirit of the DD Act:

- Ensure all members are aligned with the principles of the Council (i.e., those in the DD Act currently);
- Require that Councils participate in the screening of applicants to ensure complex membership requirements are met and that all members are deeply aligned with the values and principles of the DD Act and Council;
- Ensure timely appointments;
- Require rotation of members and a membership representative of the state; and,
- Require that the Council appoint the chairperson from among its membership.

We also recommend removing the requirement that a seat be filled by a person previously institutionalized or a family member of a person previously institutionalized. This is a difficult seat to fill and is no longer necessary.

v. What is a fair and equitable priority setting process for the Council?

The DD Act established a framework for priority setting for DD Councils that should serve as the model if the P3I program is implemented. It entails a comprehensive review and analysis and an extensively developed and refined 5-year State Plan that includes significant community stakeholder input. The Administration on Intellectual and Developmental Disabilities has a model, process, and tools that hold Councils accountable to meet the requirements of the DD Act and provide evidence that priorities are derived from the assessment of the state of the State and the input received. The State Plan that results has clearly defined goals, objectives, activities, outputs, outcomes, and performance measures.

In Maryland, the State Plan development process took 18 months. Every five years is sufficient, especially given that annual amendments can be made as long as adequate public input is sought. This thorough process has worked well and should serve as a model.

We must note that the proposed P3I program will be much more extensive because of the expanded populations, which will necessitate more time and resources to complete. Although some systems serve all people with disabilities, others are specialized. For those that do – or should – serve all disabilities, comprehensive analysis under the P3I construct would have to consider different needs of different populations. For example, making higher education available to people with intellectual disabilities involves different challenges and issues than making it accessible to people with traumatic brain injury or a physical disability.

vi. How could this be implemented, phased in?

The development of the P3I program will be complex, requiring statutory changes that will guide P3I for years to come, if enacted. To ensure the meaningful engagement at all stages of people with developmental disabilities (including people with intellectual disabilities) and their families, we strongly urge an extended phase-in.

Should the program be approved by Congress, phase in must consider federal, state and community-level needs.

- Federal: regulatory changes; training of AIDD staff and development of staff capacities; development of directives and guidance for states; development and provision of technical assistance to states; development of new State plan requirements, format, and process; development of state reporting requirements, process, and systems; and education of individuals with disabilities and their families.
- State: statute and/or executive order changes; resolution of state funding issues (for DD Councils and SILCs that receive state funds now); personnel issues (determining staff structure, staff lay-offs, transfers, and new hires); grantee phase-out; recruiting, selecting, and appointing P3I Council members; establishing operational policies and bylaws; informing the community; needs assessment and establishment of a new State Plan. (note: more phase-in time will be needed for states that require statutory action to establish their P3I Council)
- Community (individuals with disabilities, family members, state & community organizations, and service providers that benefit from Council advocacy, capacity building and system change): informing; identifying if there are any resources to replace what is lost as the result of the consolidation, including fewer staff resources and grants.

vii. What are your recommendations for how funds are distributed under this program?

We cannot recommend a specific funding approach without adequate time and information to identify options and assess their impact. We note that if this proposal is implemented and only \$45M is allocated, the P3I program will provide states nearly 60% less funding than is currently available. This will make it impossible for the P3I program to meet its stated purpose of enhancing “the availability, quality and coordination of services and supports for persons with all types of significant disabilities and their families.” Doing more with less is aspirational but not realistic. What DD Council responsibilities will not transfer over?

If it is established, we recommend that the P3I Councils be permitted to fund community-based initiatives that support advocacy, capacity building, and systems change aligned with the principles of the DD Act as DD Councils do now. We recommend *against* funding direct services unless tied to systems change or capacity building initiatives.

Regardless of what the funding mechanism would be, no state will receive adequate funding to meet the current or revised responsibilities, and individuals with disabilities will experience the effect in terms of: significantly less support for self-advocacy; fewer system change initiatives that improve child care and education, employment, and formal and informal community supports (among many other areas of emphasis), and fewer organizations increasing their capacity to help people with significant disabilities realize the principles of the DD Act in their own lives.

In conclusion:

It is not possible for the P3I program to consolidate the roles and responsibilities of the DD Councils, SILCs and TBI programs with half the funding and retain what is now accomplished by the separate, specialized entities. It will simply be impossible for the P3I program to absorb all of these responsibilities and perform well. ACL's P3I overview states that the new cross-disability state councils "will continue to engage in advocacy, capacity building and systems change to enhance the availability, quality and coordination of services and supports for persons with all types of significant disabilities and their families..." Furthermore, each state P3I Council would include, among other responsibilities:

- Strategic priority setting based on data-driven planning;
- Seeding innovation to promote system change and build capacity; and
- Enhancing the availability, quality and coordination of services and supports that persons with developmental disabilities, traumatic brain injuries and other significant disabilities of all ages and their families rely on to lead full lives in the community.

These, of course, are all important and worthy activities. However, the DD Councils have these responsibilities now and with limited funding are already forced to set priorities in order to be effective. **It is not rational to expect that expanding this charge to all disabilities while cutting the funding by more than half will even remotely lead to success. Couching the P3I program in terms that will lead people with disabilities to believe the outcomes will be better for a larger pool of people than under the current structure is disingenuous.**

Innovation, inclusion and independence will best be achieved by retaining the current structure of the DD Councils – guided by the DD Act – with adequate and stable funding.

Thank you.

ⁱ National Council on Disability, *Rising Expectations: The Developmental Disabilities Act Revisited*. Feb 15, 2011.

ⁱⁱ *A Study of the Impact and Implications of Expanding the Targeted Constituency of the Maryland Developmental Disabilities Council*. Maryland DD Council. January 1996.

ⁱⁱⁱ NACDD compilation of data from DD Council PPRs.

^{iv} DD Act; Section 124 (c) (5) (L).