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TO: Jennifer Johnson, Deputy Director
 Administration on Intellectual and Developmental Disabilities,
 Administration for Community Living

FROM: Donna Gilles, Ed.D., Executive Director, Partnership for People with Disabilities,

 Virginia Commonwealth University
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DATE: August 4, 2017

RE: Public Comment on proposed Partnerships for Innovation, Inclusion and Independence
 Program

 The Developmental Disabilities (DD) Network in Virginia is comprised of the Virginia Board for People with Disabilities (VBPD, Virginia’s Developmental Disabilities Council), the disAbility Law Center of Virginia (the protection and advocacy, or P&A, system) and the Partnership for People with Disabilities at Virginia Commonwealth University (the University Center for Excellence in Developmental Disabilities, or UCEDD). The DD Network partners submit the following joint public comment in response to the Administration on Community Living (ACL’s) request for public comment on the proposed *Partnerships for Innovation, Inclusion, and Independence* (PIII) program. The DD Network in Virginia appreciates the opportunity to provide input on this proposal.

 The DD Network opposes the proposal. The Network, which works together very effectively and efficiently on policy and systems change efforts, as required under the Developmental Disabilities Act, believes strongly that the PIII proposal is misguided and would result in less efficient and effective collaboration.  Consequently, fewer policy and systems change improvements would be achieved for the population of people with DD and their families, in Virginia, as well as the populations served by the Statewide Independent Living Council (SILC) and the Traumatic Brain Injury (TBI) Advisory Council in our state. We fully recognize that there are times when program consolidation makes sense, but this is not one of them.

 The current DD Network is an effective and efficient structure for improving the service delivery system for people with developmental disabilities, including intellectual disabilities. The DD Council (VBPD) is located in state government and focuses on policy, advocacy, and leadership development by supporting local communities by funding demonstration, training, technical assistance, and other programs. The P&A is an independent non-profit, providing systems advocacy, legal analysis, and legal representation on behalf of people with DD who have experienced abuse, neglect, and discrimination due to their disability. The UCEDD is a university-based program and provides professional training, technical assistance; conducts research; collaborates at the national and state levels for policy change; and is a partner on systems change grants within and outside of the network. Together, as sister organizations, operating within and outside of state government, we are able to influence policy and practice on the inside and the outside, and collaborate to ensure that we maximize our individual and collective strengths to serve people with DD. The DD Act allows and demands that we do this. Removing the DD Councils from this existing structure by changing the Councils’ mandates and expanding the population that we serve would irreparably damage our partnerships and the intensive collaboration that we currently undertake=.

In response to the specific questions noted in the solicitation for public comment, see below:

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

 The central purpose of the State Councils on Developmental Disabilities (DD Councils) as stated in the DD Act is “to assure that individuals with developmental disabilities and their families participate in the design of and have access to needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, and integration and inclusion in all facets of community life, through culturally competent programs.” DD Councils are unique in that people with developmental disabilities, who have first-hand knowledge of challenges in the state, are the majority of the people who provide input into the development of the state’s plan to address those challenges and create seamless and efficient service systems. Sixty percent of the membership of the Council consists of individuals with developmental disabilities and their families.

If this sole focus on people with developmental disabilities is lost, the Council’s ability to meet their needs as mandated in the DD Act will be greatly diminished. Too often, the needs of individuals with developmental disabilities do not receive attention because they only account for approximately 5 million of the over 50 million people with disabilities nationwide. In Virginia, there are approximately 147,000 people with developmental disabilities who would be under-represented if the Council’s population expands to include people with traumatic brain injury and all other disabilities, as per the PIII proposal. Most vulnerable would be those children, youth, and adults who have the most significant disabilities.

 Several other features of DD Councils are also integral to fulfilling the Councils’ purpose. Preserving the features listed below is critical.

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* The authentic voice of self-advocates and family members are included in all aspects of the process of creating supportive communities, including but not limited to ensuring that at least 60 percent of the entity is composed of people with developmental disabilities and their family members.
* DD Councils are comprised of people who are experts in DD and related disabilities. It is critical to keep that knowledge and expertise as a key component of any new entity. People with DD and their families make the decisions regarding the laws, policies and practices that affect them.
* DD Councils like VBPD have an organizational infrastructure and the ability and responsibility to act independently. The Governor or designee of the state signs a non-interference assurance when the Council state plan is submitted, assuring that the Council will be able to perform its work without undue influence from the administration. DD Councils are the sole entity responsible for advising the Governor, legislators, and other policymakers on the specific needs of people with DD based on a federal legislative mandate. Thus, DD Councils are uniquely able to provide programmatic and policy advice at the highest levels of state government in order to improve services and supports within the state or territory. This is true even if the DD Council’s position is not in sync with that of other state entities.
* The DD Council is able to serve as a catalyst and convener for bringing together the DD community, which includes state agencies and others, who are interested in, and concerned about, the needs of people with DD. Councils must remain legislatively connected to the other DD Network partners in the DD Act.
* The DD Council is the only entity that provides direct support to communities by funding grants that improve services and supports and are designed to effect systemic change and build the capacity needed in that community (or region) in order to ensure that people with developmental disabilities of all ages can lead full lives in the community.
* The DD Councils are the only entity that conducts a statewide assessment of needs of people with developmental disabilities across the lifespan in early intervention, education, transportation, employment, healthcare, community living, housing and more.
1. 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?

 The Network does not support this proposal. Each of the Councils that would be part of the PIII influence and/or provide services and supports to very different segments of the disability community. The DD Council serves people with developmental and intellectual disabilities, which are manifested before the age of twenty-two. The SILC serves people with all disabilities of all ages, while the TBI Council serves individuals with traumatic brain injuries. Furthermore, the DD Council is the only entity that has an organizational infrastructure, and the only one that operates independently. In Virginia, both the SILC and the TBI Council are advisory and are located with the state’s vocational rehabilitation agency, the Department for Aging and Rehabilitative Services. The SILC’s primary role is to develop and oversee the state plan for Independent Living Services and serve as a flow through entity for funds that go to the Centers for Independent Living to implement the plan. The TBI Council advises the lead state agency for brain injury, DARS, on services and supports needed by that population. Neither the SILC nor the TBI Council has autonomous operations or authority.

 Combining these divergent populations and roles would inevitably reduce the effectiveness of the Council, while yielding no additional synergies. In Virginia, there is a 39-member DD Council that meets all of the federal and state requirements for composition. Incorporating representatives of disparate disability populations, additional state agencies and policy experts would result either in increasing the size of the Council to an unmanageable size, or in diluting the voice of people with developmental disabilities and their family members on the Council. Either would have the effect of decreasing the effectiveness of the Council as a voice for the underrepresented and historically marginalized population that it was created to serve: people with developmental disabilities. It would also make consensus much more difficult to achieve. The priorities and strategies of these different disability populations are often quite different. For example, the DD Council does not support disability specific waivers; however, the traumatic brain injury (TBI) community has long advocated for a TBI specific waiver. We respect their judgment and their positions; however as one Council, reconciling divergent positions such as these would make decision-making on behalf of any or all of the populations much more challenging.

Furthermore, there is already significant collaboration among the entities. The Council has a seat on the TBI Advisory Council and has an excellent relationship with the SILC and significant collaboration with the Centers for Independent Living across the state. Each party respects the voice of the others, work together on issues of mutual concern but also address issues specific to their populations. This would be diluted through consolidation.

1. What are the challenges that can be addressed?

 The most effective way to address the challenges is to abandon the concept of PIII. ACL should instead identify the goals it is seeking to accomplish and seek widespread feedback on the best means to meet those goals. The proposed funding of $45M for all three entities, representing a cut of $57M, will most assuredly lead to the failure of the DD Act to fulfil its promise to people with developmental disabilities. With the proposed funding cut, the DD Councils could not achieve their current mission and mandates given that funding just for the Councils is $73M. Many states, especially minimum allotment states, have been increasingly challenged to deliver services and supports. In Virginia, Council funding has been flat for nearly 15 years and funding for DD Systems change initiatives are already inadequate. With costs increasing, VBPD has already had to conserve resources by moving to a biennial grant cycle and reducing the frequency of its leadership and advocacy training by half. If these funding cuts were implemented under the current structure, DD Councils would have to eliminate programs and staff and significantly reduce investments in the community. Given the difficulty in serving just one population with the proposed funding, it would be impossible to serve all three populations with the proposed funding. The National Council on Independent Living has stated that “cuts to the IL Program will result in a reduced ability to serve consumers, major cutbacks…and even CIL closures.” In fact, a significant funding increase would be needed in order to combine all three programs into one new or existing entity with multiple constituencies, multiple and divergent needs assessments, plans, reports, and activities. No savings would occur from consolidation, only significant loss of services and capacity.

 The DD Councils, SILCs, and TBI state grant programs each serve a different segment of the disability population.  While there may be some overlap for those diagnosed before age 22, there is also significant variation in terms of the policies, practices, programs and supports needed to serve each population type. It will be challenging to form one Council that would be able to effectively and efficiently address the variety of needs with respect to laws, policies, practices and supports for such disparate populations, having different ages of onset or diagnosis as well as type and severity of disability. As noted above, it will be even more challenging to reach consensus on how to expend limited funds for divergent populations, all of which have their own stakeholder constituencies.

 DD Councils, SILCs, and TBI state grant programs are authorized in separate and distinct pieces of federal legislation. The SILCs and TBI state grants were reauthorized in 2014.

The programs are funded differently (competitive (TBI) versus formula grant (DD Council). The programs are also authorized by different congressional committees.

 DD Councils operate as independent and objective agencies, while the SILCs and TBI state grant programs do not. The DD Act currently requires the members of the DD Council to be appointed by the Governor and answer to the Governor; however, the Governor and his or her Administration and others may not interfere with the DD Council meeting its responsibilities in the DD Act. This ensures that the Council is not politicized, particularly when there is a change in the political party of the gubernatorial administration. Virginia’s DD Council is non-partisan and has worked successfully with Administrations of both parties to achieve change, as the Council is seen as an independent and objective voice. SILCs and TBI grant programs report to an agency in Virginia, the Department for Aging and Rehabilitative Services, and are not independent, but rather advisory.

 Combining the diverse populations under the PIII proposal would dilute the voice of people with intellectual and developmental disabilities. The DD Act requires the DD Council membership to be reflective of the different demographics of the population in the state or territory. DD Councils recognize that disability also has many intersections. People with disabilities want and need to identify themselves in many ways and bring their cultural and linguistic heritage to the process of improving policies, services and supports in the state or territory. Ensuring that all voices of the community have a place at the table is critically important.

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

 The DD Councils currently must follow a very explicit process established in statute that allows for a fair and equitable process for priority setting. For 47 years, the DD Councils have worked to create a five-year State Plan in each state and territory. Prior to the beginning of a five-year cycle, the DD Councils must conduct a comprehensive review and analysis of the extent to which services, supports, and other assistance are available for people with DD and their families and the extent of unmet needs for services, supports, and other assistance for those individuals and families. The lengthy process includes public input from across the state/territory and is very transparent. The DD Act requires the DD Councils to write goals that Councils must work toward along with objectives that must be measured. DD Councils report their measurements back to AIDD, Congress, their state, and the public each year. The DD Councils have the most comprehensive and data-driven State Plan amongst the three PIII entities. The level of data review and analysis required by the current DD Council state plans could not be accomplished for all three population segments without significant additional resources than those that are proposed.  This process would in fact be destroyed by the PIII proposal. The merging of vastly different disability groups, combined with dramatic funding cuts, would make it virtually impossible to conduct priority setting in a way that full enables people with developmental disabilities and their families to fully participate.

1. How could this be implemented, phased in?

 We do not support the creation of the PIII program. Creation of any new program takes significant time and phased in, thoughtful implementation for it to meet its intended purpose. We believe that, at a minimum, the process must be slowed down considerably to ensure that there is adequate input, discussion, and consensus building. The process of developing a plan for any consolidation or restructuring cannot be completed within two months. A minimum reasonable time just for consideration of a proposal should be two years. The proposal would require changes to the DD Act and the Rehabilitation Act along with their implementing regulations and would require changes in the state laws that establish and mandate the responsibilities of the three Councils. The proposal is unwise and does not accomplish anything meaningful. It dilutes the ability of all three partners to fulfill the mandates provided to them under divergent federal and state laws.

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

 The proposed funding amount of $45 million is completely inadequate to serve any of the populations in an efficient or effective manner. As noted above, the DD Council is a formula grant; the TBI Council is a competitive grant, currently only awarded in 19 states; and the SILC is a pass through for funds that go directly to the Centers for Independent Living. The DD Councils currently have a complex formula that addresses population and needs, and which should be continued as it has been proven to be an effective mechanism.

 Here is a snapshot of the work of the DD Council, just over the last five years:

**DD Councils Change Lives by Changing Systems**

The Virginia Board for People with Disabilities (VBPD) improves the lives of people with developmental and other disabilities in the Commonwealth of Virginia by strategically funding grants, influencing public policy, and training people with disabilities and their family members to more effectively communicate and advocate for themselves and their communities. VBPD works with its DD Network partners to ensure that people with developmental disabilities can live independent and productive lives in the community with the supports and services that they need to maximize their potential.

**How we do it: We fund innovation, improve policy, and empower emerging leaders**

| **Systems change grants** VBPD strategically funds grants and contracts to effect systems change, improve existing policies and practices, and demonstrate new approaches to solving problems.  | VBPD awarded 20 grants and contracts and leveraged an additional $441,000 in non-federal funds for projects that:* Increase the availability of accessible housing in the Commonwealth
* Increase employment opportunities for people with developmental disabilities
* Improve transportation coordination in rural areas
* Empower people with developmental disabilities to protect themselves from abuse, neglect, and exploitation
* Improve secondary school outcomes for students with disabilities
* Improve outcomes for infants who have spent time in a Neonatal Care Unit by increasing access to early intervention services.
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| **Improving Public Policy** VBPD ensures that policy makers in the Commonwealth have the information that they need to make informed decisions and that the interests of people with developmental disabilities are considered during policy, legislative and budget deliberations   | 128 policies and programs were created or improved through Council activities and collaboration with the P&A and UCEDD, including policies that: * Advance an Employment First policy in the Commonwealth
* Improve housing policy to expand options for people with DD
* Expand access to community-based supports
* Protect people with DD from discrimination, abuse and neglect
* Advance legislation to regulate the use of seclusion and restraint in public schools
* Prevent institutionalization of people with DD
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| **Empowering advocates** VBPD trains individuals with developmental disabilities and their family members in self advocacy, self-determination, and leadership along with other areas related to the Board’s goals and objectives | 4,327 individuals were trained to enhance their leadership skills, increase their knowledge, and more effectively communicate with policymakers* Self advocates and family members have obtained membership on numerous boards and leadership coalitions, including the P&A Board and the UCEDD Advisory Council.
* Training program graduates are participating in a VBPD program designed to help them remain engaged in promoting systems change.
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