

November 27, 2017

Tom Massey
Interim Executive Director
Colorado Department of Health Care Policy and Financing

Cc: Gretchen Hammer, Jennifer Martinez, Bonnie Silva, Colin Laughlin, and Dan Krug.

Re: HCPF Restructuring

Dear Director Massey,

We write today to express concern about the proposed restructuring of the Office of Community Living within HCPF.

We acknowledge and appreciate HCPF's goal in restructuring the Divisions for Intellectual and Developmental Disabilities (IDD) and Long-Term Services and Supports. We agree that an efficient organizational structure is critical to any entity's function, and we applaud efforts to improve processes at HCPF to expedite work.

We do, however, have concerns about the loss of a division director for IDD and, therefore, the loss of a voice within HCPF that can be a champion for this unique population. To provide context for our concerns, we think it is helpful to look back at the evolution of IDD services nationally and in Colorado.

The first services for people with IDD were funded by state and federal programs outside of Medicaid, and guided by the principles of the first iteration of the Developmental Disabilities Assistance and Bill of Rights Act (DD Act). It wasn't until the 1980s and the creation of Home- and Community-Based Services waivers that Medicaid became the primary funder of supports. As a result, state and federal Medicaid agencies have had increasing authority to shape IDD policy. This shift has occurred in Colorado as well.

In 2013, the Colorado General Assembly passed HB13-1314, which transferred the administration of programs for people with IDD from the Department of Human Services to HCPF. In response to stakeholder concerns about a loss of focus on the unique needs of people with IDD in the transfer, the General Assembly created an Office of Community Living and a Division for Intellectual and Developmental Disabilities within HCPF. Section 25.5-10-203 C.R.S. outlines the creation and function of the Division for Intellectual and Developmental Disabilities, with reference to the division's "unique goal...in administering lifelong programs, services, and supports for persons with intellectual and developmental disabilities..." We believe that the Division has been successful in carrying out the principles of the DD Act and made positive strides for people with IDD and their families. It is because of this success that we are concerned about losing the expertise and unique focus on this population in HCPF's plans to restructure.

People with intellectual and developmental disabilities are a unique population. They typically have significant needs that continue indefinitely throughout the lifespan. They are at a greater risk of abuse, neglect, exploitation, and violation of their legal and human rights than the general population and even those with other disability types. And they require more human and financial resources as they need more comprehensive supports across many areas of their lives.

While many of the Medicaid-funded services they receive may be, on their face, the same in type and definition as those for other populations, the difference in actual delivery is subtle and difficult to describe. It involves supporting the development of skills that a person has never obtained (habilitation) versus helping them regain lost skills (rehabilitation). It involves building a person's independence, creating an environment that is sensitive

to both physical and behavioral challenges, and taking extra time and effort to ensure that the person is consenting and comfortable in the provision of services. It involves dedicated time and effort to resolving co-occurring conditions and developing ways of communicating with people who don't use words or written language.

It is for these reasons that, prior to the DD Act, people with IDD faced almost complete exclusion from schools, communities, and even homes. It is for these reasons that the DD Act recognized the need for a focus on the needs of this unique population. And it is for these reasons that the General Assembly recognized these unique needs and created a specialized division within HCPF to oversee and direct IDD policy and programs. Our concern, therefore, is that the expertise housed in the current division will become fragmented, and the focus on this population will increasingly be lost over time. Given the complex and fragmented nature of our service system already, it would be an incredible disservice to people with IDD and their families if it became more so.

Meanwhile, there are multiple and complex systems changes underway for this population that will require leadership and strong change management oversight within HCPF. We believe that developing coherent public policy in this area will require the leadership of someone with expertise in IDD to oversee all of these various initiatives and provide direction to the four new OCL divisions as they are implemented. In order to fulfill this role and maintain a separate and distinct focus on the needs of people with IDD, we recommend that HCPF select a "Director of the Office of Community Living and Intellectual and Developmental Disability Policy" to fill this role. We believe it is critical that this person have a focus separate and apart from the rest of Medicaid, but also be in close communication with the current Medicaid director, Gretchen Hammer. The Director would oversee activities of the four divisions to ensure coordination among them for initiatives and programs for people with IDD as well as other waiver populations.

It is our sincere hope that selecting a Director of the OCL and IDD Policy will allow HCPF to make the necessary structural changes it needs for efficiency while also holding true to the legislative intent of HB13-1314 to maintain a focus on this unique and important population. We thank you for your considerations of the issues outlined above, and are committed to working with HCPF to ensure that the restructuring is successful and improves outcomes for people with IDD and their families.

Sincerely,

