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November 5, 2019

Dear Medical Services Board Members:

Re: Proposed Rule 18-10-18-A Concerning Pooled Trusts

I am the Executive Director of the Colorado Fund for People with Disabilities (CFPD) and I am writing today to **urge you to oppose the proposed rule concerning Pooled Trusts** that will be introduced by David Smith. We believe that the proposed changes need to be introduced as a legislative change to the statute as they contain substantially different agency interpretations of the rule and are **not under the authority of the Medical Services Board through rule making**.

I would like to call your attention to three major points.

- CFPD is opposed to the proposed regulation, which we believe is illegal.
- CFPD has engaged in the stakeholder process with the Department of Health Care Policy and Financing (the Department).
- The proposed rule change would have a substantial impact on the 1200+ low-income, individuals with disabilities currently served by CFPD as well as limit our ability to provide additional services in the future.

1. CFPD is opposed to the proposed regulation. Please see Exhibit A outlining our position and the Federal and State Statutes that support our position. See also the memo from our attorney, Tammy Conover, sent separately and Exhibit B.
2. CFPD has engaged in the stakeholder process with the Department of Health Care Policy and Financing (the Department).
    a. May 30, 2019: Meeting with the Department in re: current pooled trust beneficiaries with trusts funded after the age of 65. The Rule was given to us at the conclusion of the meeting.
    b. September 13, 2019: CFPD, along with other stakeholders[1], attended the Medical Services Board meeting and gave testimony during the Public Comment Period in re: it's Opposition to the Proposed Rule. David Smith initially introduced Pooled Trusts during this meeting but did not circulate the proposed rule to the Medical Services Board.

[1] Stakeholders who have attended meetings with the Department have represented CFPD Board and Staff, Arc of the Pikes Peak Region Pooled Trust, Disability Law CO, Colorado Cross Disability Coalition, Members of the CO Bar Association Elder Law Section – specifically the Medicaid Regulatory Committee; Elder Law Attorneys in private practice, Family members of those affected by disability.

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c. September 23, 2019: CFPD and stakeholders attended the Public Rule Review Meeting. During that meeting, David Smith and his staff stated that maintaining the status quo of the current rule was untenable. The Stakeholders present at the meeting, including the CO Bar Association members, expressed their opposition to the proposed regulations. The Department asked stakeholders for proposals which would address their concerns. Stakeholders asked for a delay in the rule so that we would have time to develop and submit the proposals to the Department and engage in future meetings.

d. October 4, 2019: CFPD submitted four different proposals to the Department for their review. See Exhibit C.

e. October 7, 2019: CFPD meeting with the Department and stakeholders to discuss CFPD's proposals. One of the staff from the Department said that proposal #3 was "great". The Department began discussions about a counter proposal considering a "true up" in terms of a payment to the Department at the end of the year if funds were not spent.

f. October 10, 2019: the Department sent a Response to CFPD Proposal Concerning Proposed Pooled Trust Regulations. See Exhibit D.

g. October 18, 2019: CFPD Attorney Tammy Conover sent an email to Jennifer Weaver of the Attorney General's office with CFPD's counter to the Department's response dated 10/10/19. See Exhibit E.

h. October 21, 2019: CFPD and other stakeholders met with the Department for the Public Rule Review meeting in preparation or the Medical Services Board meeting on November 8th. At this meeting, David Smith reported that despite making great progress in our discussions, he now believed we were "miles apart". CFPD continued to contend that this rule change is a substantial change to the rule and that it needs to be a change to the statute.

   At this point of the meeting CFPD again asked for a Cost Benefit Analysis. During the remainder of the meeting and in email correspondence following, Chris Leoniak of the Department asked a number of questions about CFPD's operations.

i. October 31, 2019: CFPD and other stakeholders received notice of the proposed rule being published. The Regulatory Analysis is Exhibit F.

3. The proposed rule change would have a substantial impact on the 1200+ low-income, individuals with disabilities served by CFPD. As part of the Regulatory Analysis, the Department shall provide a description of the probable quantitative and qualitative impact of the proposed rule, economic or otherwise, upon affected classes of people. The Department provided a simple three sentence response to the question, which reads as follows:

> "The Payback Provision will decrease revenue for trust companies that currently retain 100% of any leftover amounts in pooled trust sub-accounts following the death of the beneficiary. These impacted companies may be required to change business practices

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> and/or develop revenue from other sources if the proposed rule is adopted. The Penalty for Over 65 Transfers will disallow disabled individuals over the age of 65 to transfer assets into a pooled trust or create a pooled trust for the purpose of maintaining resource eligibility."

From CFPD's perspective, it does not appear that the Department has performed a full analysis in regards to the impact to the individuals served by CFPD, specifically from its Charitable Fund. (CFPD refers to the retained funds as retained funds or Charitable Fund). According to the Master Pooled Trust Document, which was developed and adopted by the Board of Directors on February 13, 1994, and then approved by Colorado Medicaid at that time and each time it has been amended in 2000, 2008, 2010 and most recently in 2011,

> "Upon the death of a Beneficiary, any amounts remaining in the Beneficiaries Trust sub-account shall be deemed to be surplus Trust property and shall be retained by the Trust and, in the Trustee's sole discretion, used (a) for the benefit of other Beneficiaries, (b) to add indigent disabled persons, as defined in 42 U.S.C. 1382c(a) (3), to the Trust as Beneficiaries, (c) to provide indigent disabled persons, as defined in 42 U.S.C. 1382c(a) (3), with equipment, medication or services deemed suitable by Trustee. (d) for such other charitable purposes as the Trustee may determine consistent with the intent of the Trust."

CFPD requests that the Medical Services Board ask the Department to consider the following qualitative and quantitative impacts to individuals served by CFPD.

a. Payback Provision. If HCPF is successful, what happens to/when…?
   1. Charitable Organizational Rep Payee program that currently serves 110 individuals. These individuals are referred to CFPD by Adult Protective Services, Social Security, Guardians, Conservators, Courts through the Public Administrators, family members, mental health centers, community centered boards, Arcs, etc. This program is supplemented by CFPD's retained funds through the current 100% payback provision. This CFPD Program lessens the strain on all of the entities who are currently referring people to CFPD. Most importantly, it ensures access to the basic human needs of shelter, food, clothing and medical care for the individuals served.
   2. An individual was a beneficiary of the pooled trust and explained to his pooled trust case manager that he wanted to leave his Medicaid paid nursing facility and his brother/guardian was preventing it. With the use of CFPD's retained funds, an attorney was hired with CFPD's retained funds and he moved to a less restrictive/less costly community setting with a new volunteer guardian.

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3. A pooled trust beneficiary lost her housing due to the flooding several years ago, CFPD used its retained funds to buy her a new trailer for her and her minor child when insurance and FEMA did not cover the costs. This action likely prevented a strain on child protective services, homeless shelters and other charities.
4. A pooled trust beneficiary had a family member move into her condo and try to list it for sale, CFPD petitioned the court on an emergency basis for a conservator to be appointed to secure the property. The attorney and conservatorship fees were paid by CFPD's retained funds. This likely prevented a move to more restrictive environment and most definitely averted financial exploitation of an at-risk adult, which would have included the resources of the courts and law enforcement.
5. Our Rep Payee Coordinator picks up the phone and agrees to serve as Rep Payee because no one else will. Until a Rep Payee can be appointed, and the funds are held up by the Social Security Administration and a person does not have access to them.
6. Our Rep Payee Coordinator picks up the phone again and agrees to serve as Rep Payee for a woman with severe mental illness who has been found by the police after her remaining parent died. These SSA funds are then used to pay for her room and board at her group home and Medicaid pays less.
7. Our trust case manager gets a call from a community member about likely online financial exploitation of an at-risk adult, she immediately talks to the beneficiary and applies for CFPD to be the Rep Payee to cut off the funds going to the exploiter.
8. The 37 individuals with Intellectual/Developmental Disabilities experiencing homelessness who received temporary housing from CFPD's Charitable Fund for nearly three months. This prevented a strain on shelters and other community providers during this time.
9. The beneficiary of a disability trust who constantly asked CFPD, as trustee, to pay for her basic needs, despite healthy SSDI income. We suspected she was exploited by others. She agreed with CFPD becoming her Rep Payee and she now has plenty of money in her conserved SSDI funds and the spending from the trust has decreased significantly.
10. A Conservatorship is terminated and the Guardian Ad Litem or Guardian documents that a Guardian and/or Conservatorship is no longer necessary due to the case management provided by CFPD. This reduces the impact to the courts, and already strained professionals providing reduced or pro bono services.

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11. CFPD is asked to step in (on more than one occasion) when a successor Trustee, Rep Payee, Conservator, other fiduciary has stolen all or most of the money.
12. A pooled trust beneficiary with a major mental illness suffers a stroke, and his CFPD case manager visited his home and found that he had been discharged home inappropriately. He was living in a contaminated and unsafe environment and he was at risk medically. She worked with his other supports and helped him to apply for a Home and Community Based Services Waiver to meet his needs since he was adamantly against moving to a skilled nursing facility. This advocacy for his independence also led to a cost savings to Adult Protective Services and Medicaid LTC.
13. CFPD educates the community (and this is at least twice a month but typically more) on being a Trustee, Rep Payee, what to look for in hiring a Trustee, etc. which likely prevents further mismanagement of trusts and other financial accounts by family members.

b. 65+ funding a trust over the age of 65. If HCPF is successful, what happens to…?

1. Someone like Mary, the first beneficiary of CFPD's pooled trust, an 88 year old woman living in a skilled nursing facility, who joined the trust on March 20, 1994 with $12,500 derived from a personal injury settlement against the nursing home for severe abuse and neglect.
2. Or someone like Barbie who has had an intellectual/developmental disability since birth. She has been on Medicaid services through the Comprehensive Services Waiver for many years. As many of you know, the waiver has a long waiting list and is very difficult to get on. Barbie received a back-payment in Social Security for $8,000. Under the proposed rules, she would have to spend down immediately instead of setting the funds aside to pay for medical services not otherwise paid for by Medicaid, clothing and trips during her life expectancy.
3. Or someone like Patrick who had a stroke at the age of 55 and then was hit in a crosswalk while using his wheelchair to cross the street when he was 75. Patrick's daughter reports that the funds in her father's pooled trust to provide accessible transportation to family events, to install accessibility features to his apartment so he did not need to move into a nursing facility (a much greater expense to Medicaid).
4. Examples of other health and safety trust distributions that CFPD regularly pays for:
    i. Accessible Vehicle Maintenance
    ii. Wheelchairs or other mobility devices
    iii. Professional Guardianship Fees

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iv. Dental Work
v. Technology to keep people in a less restrictive setting
vi. Transportation
vii. Community Activities and companionship
viii. Therapies not covered by Medicaid
ix. Other equipment not covered by Medicaid to enhance quality of life

In conclusion, I urge the Medical Services Board to consider all of the ways in which CFPD's services are benefiting our community in Colorado for people with disabilities. CFPD is the largest pooled trust in located in Colorado and, to my knowledge, is the only pooled trust that consistently uses its Charitable Fund to give back to our local, Colorado community and to provide services and supports to address unmet needs or underserved populations while reducing the financial impact to other state agencies and private entities.

Sincerely,

Megan Brand

Megan Brand
Executive Director, CFPD