

For people with intellectual and developmental disabilities

The Arc of Massachusetts

217 South Street Waltham, MA 02453-2710 781.891.6270 arcmass@arcmass.org www.arcmass.org

## Achieve with us.

Scott Borchardt President

Leo V. Sarkissian Executive Director

October 18, 2021

Kilolo Kijakazi Acting Commissioner Social Security Administration 6401 Security Boulevard Baltimore, MD 21235-6401

Submitted via <u>www.regulations.gov</u>

Re: Response to SSA's Agency Information Collection Activities: Proposed Request, 86 FR 46307 (August 18, 2021), Docket No: SSA-2021-0029

Dear Acting Commissioner Kilolo Kijakazi:

We write in response to the Social Security Administration's (SSA's) burden estimate regarding the time it takes to complete Form SSA-454-BK or the Continuing Disability Review (CDR) form. There comments are submitted on behalf of The Arc of Massachusetts. As a statewide advocacy organization, we work with many individuals who have intellectual and developmental disabilities, their families and organizations which assist them. We must disagree with SSA's estimate.

- Many of our constituents cannot fill out the form on their own. Instead, they rely on family, friends, or service providers. It is not simply completing the form but finding help that takes time.
- The present workforce crisis, has resulted in far fewer direct support available to assist in such forms
- In Massachusetts, over 70% of constituents live with family members, and 17% live with *older* caregivers. Family members have other responsibilities in addition to caregiving. The workforce shortage also affects families who require in-home assistance; many are going with staff and day services.
- The form is 15 pages long with multiple narrative questions about the beneficiary's medical treatment, including many details that the beneficiary or those assisting them might not know without assistance from treating health care professionals.

The form can require hours of work from people with disabilities and their families, but the amount of time varies depending on conditions and resources. We can confidently say that 1 hour is a completely inaccurate estimate of the time burden of this form.

We hope SSA will revise their burden estimate and take steps to simplify this form and reduce the burden it places on people with disabilities and their family, friends, and service providers.

Thank you for the opportunity to comment on this form.

Sincerely,

Leo V. Sarkissian
Executive Director