# AUCD IDDRC Call 5/5/20

## -  Policy Updates

* COVID 3.5
  + Small business loan replenishment
  + Hospital and clinical care providers – more broad and flexible
* Package 4 next steps/timing
  + Advocacy for HCBS - focus on IDD that has been absent in previous supplemental appropriations
  + DD systems have pivoted to COVID response but lack of funding to do so
    - Older American Act programs were funded in COVID 3 for similar reasons
  + School settings
    - Remote learning is accessible and equitable
    - AUCD IDEA white paper - attached
  + Friends of NICHD
    - Raising issues in a letter to the Hill
    - Call out to the expertise of the IDDRC community
  + AUCD FAQs
    - [**COVID-19 Emergency Supplemental Funding Packages** -](https://www.aucd.org/template/news.cfm?news_id=14645&parent=16&parent_title=Home&url=/template/index.cfm?)Funding Directed to State, Local, Territorial, and Tribal Governments
    - [**Frequently Asked Questions (FAQ) Re: COVID-19**](https://www.aucd.org/docs/urc/FAQ_COVID19.pdf) - Information in this Frequently Asked Question document is here to help you continue UCEDD core functions during the COVID-19 pandemic. AUCD and the UCEDD Resource Center will continue to update this document as needed.
    - [**Frequently Asked Questions (FAQ) 2.0 Re: COVID 19**](https://www.aucd.org/docs/urc/COVIDFAQ2.0.pdf) - You can find the Frequently Asked Questions (FAQ) Re: COVID-19 on the UCEDD Resource Center.  Information in this Frequently Asked Question document is here to help you continue UCEDD core functions during the COVID-19 pandemic. AUCD and the UCEDD Resource Center will continue to update this document as needed.
  + IDDRC director letter for NICHD funding
    - Possible avenues:
      * Supplemental funding ask
      * Highlight IDD populations, disparities, data needs, and services
        + Data collection: need for distribution lists
      * Raise the work of IDDRC to not be threatened by cuts later in year
    - Timeline: After package 4
* CDC
  + At risk taskforce combined with community mitigation taskforce – disability still embedded in their work
  + New updates on CDC guidance
    - [Children with special health care needs](https://www.cdc.gov/coronavirus/2019-ncov/faq.html#Children-and-Youth-with-Special-Healthcare-Needs)
    - [Disability Groups and Risks](https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html)
      * Direct care providers guidance is a component of this
  + Friends of CDC NCBDD
    - Genetic Alliance – [Clinic Trials Done Differently Webinar](http://www.geneticalliance.org/about/webinararchive)
  + AUCD Public Health Webinars
    - [Public Health Webinar Series on COVID-19](https://www.aucd.org/template/news.cfm?news_id=14624&parent=16&parent_title=Home&url=/template/index.cfm?)

## - NICHD

* Research is important to understand impact. Opptys:
  + PA #s: 20-097 & NOT-OD-20-097
* RDCRNs (Rare Disease Clinical Research Network) – rare disease survey on family impact of rare disease in family and COVID – attached

## - IDDRC members

* Info to share on what your centers/programs are doing?

- The ‘new normal’

* States re-opening; vulnerable populations still in place
  + Addressing direct care, in-home supports
  + Impact on clinical care
  + Telehealth
* Will will/should care look like for IDD in a post COVID world? (discussion)
  + IRB impact is variant and NIH is not making universal guidance
  + Impact of ratio on IDD research and treatments going forward
* Development of a white paper/policy brief
  + John Constantino taking lead – agenda for call tomorrow
  + Different audiences
  + Multiple formats: journal commentary, policy brief, op-ed etc
  + Thinking about consequences, opportunities, missed opportunities, etc