# 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