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# IDDRC Network Call Notes: April 16, 2020

## Update on AUCD efforts

* AUCD Network calls every Thursday from 4-5 p.m. EST. All are welcome.
  + <https://zoom.us/j/910436386?pwd=QnRGR3QwcHp6dnFtMHlaeUpLTXUyUT09>
* Center for Human Dignity for PWD – at the Cincinnati UCEDD – has funds from ACL
  + Focus on civil rights in a COVID context ([fact sheet](https://www.ucucedd.org/wp-content/uploads/2020/04/Center-for-Dignity-in-Health-Care-fact-sheet-on-rights-for-people-with-disabilities.pdf?fbclid=IwAR2TNfAwDNf5zpVT7AwM4KQH4i8jN4vBCWCqSpYrgq-HLnAnLHknAX1JblM))
* FEMA Disability Integration Office – MOU with AUCD developed and near completion
* Coalition work
  + Multiple webinars featuring AUCD staff and network members held in partnership with other disability organizations
  + Sharing priorities with members of Congress and federal agencies
  + Messaging and communication is streamlined
* Major issues raised by the Network where AUCD is actively engaged in advocacy efforts:
  + Data: Profound lack of disability (and disability subpopulation) data
  + Civil rights: rationing of medical care and equipment; monitoring of state policies in a disability context
  + Food security for those with disabilities and their families who are isolated
  + Supplemental income for people with disabilities; preventing adverse effects on their government-funded program and service eligibility
  + Technology: issues of access to broadband connections, appropriate, accessible technology, and training on the use of technology
    - Broad implications for access to telehealth, education, supported employment, and social isolation
  + Access to (largely non-credentialed) direct support professionals, personal care attendants, paraprofessionals, and others whom people with disabilities rely on for ADLs and IADLs.
  + Continued access to Medicaid-funded home and community-based services, largely non-medical services, that preserve community (vs. institutional) living
  + Plain language resources are needed for individuals with I/DD and their families
* AUCD is hosting 4-part Public Health Webinar Series, as part of our cooperative agreement with CDC
  + <https://www.aucd.org/template/news.cfm?news_id=14624>
  + not aware of any additional funding available for COVID-19 research yet, but grant office is offering extensions
* CDC website now offers disability-specific information that AUCD has helped review and vet
* Sharing the needs were are hearing from the Network on plain language with APHA so we can partner on teaching others to create plain language materials that are accessible in the response

## Needs for data

* Sahin: First case in Boston was teenager girl with I/DD
* ASAN ([www.asan.org](http://www.asan.org)) has received funding to track infections, hospitalizations, and deaths due to COVID of people with disabilities in congregate settings
* Melissa from NIH
  + NICHD has not benefitted from supplemental NIH funding for research on COVID
  + trying to support research on pregnant mother, children, those w I/DD
  + Trying to utilize existing funded partners to capture quantitative data
    - Ex: Maternal fetal medicine unit
    - Trisomy 21 research community – survey to healthcare providers = not successful so shifting to families
    - Are there rudimentary registries that could be developed across the IDDRC network?
* Sahin: International partnerships to gather data in I/DD, setting, medicine, etc – surveys distributed to families
* Kornblum: U of California system-wide use of Epic EHR; opportunity to pull data based on ICD-10 codes to gather COVID-specific information

## Needs for Research and Advocacy

* Constantino: Confidence gaining on human contact – is there enough information dissemination to keep those with I/DD safe and interact with DSPs and others?
  + Challenge with limited PPE
  + Plain language resources needed
  + Shift to telehealth – educating clinicians to ensure it’s accessible and families and PWD know their rights
* Bookheimer: Need for in-person therapies for some children still great -  PT or ABA
* Tracy King: highlighting digital divide
  + Critical need
  + Jeff: Rett Syndrome – televisit for rare disabilities to meet need of disparity, so yes access to technology and wifi but cheaper than moving people to specialists
    - John: policy complications of Medicaid reimbursement
      * Lack of payment for devices and internet access
      * Prohibition (by all payers/insurers) for interstate services
* Bookheimer: added COVID questions to ABD research

## Long term impacts

* Piven: Gather clinicians across centers to deliver care in this situation
  + Triage role in medical centers – clinic patients are on hold as not urgent – switching to urgent care to serve as experts to manage care around IDD patients
* Sahin: quick shift on clinical trials
  + Fatemi: impacts on basic labs to IRB closures – ethics and safety perspective, what is the right thing to do?
    - If scope of research is in person, you can’t consent them online; research has to be all online
* Constantino: long-term, internet-based society
  + Develop list of priorities to move forward in delivery of care
  + Develop an IDDRC commentary or Policy Brief?
    - Piven: online conference, white paper re: IDD in post COVID world

## Next Steps:

* Report back from this meeting to be provided on May 6 IDDRC Network call
* Reconvene group in two weeks

## Chatbox:

* It would are great to circulate the resources dropbox again.
* Hi all, This email just came in inbox through the NIH OBBSR listserv, may be of interest re: data collection efforts - COVID-19 Specific Survey Items Now Available on PhenX and the NIH Disaster Research Response (DR2) Platforms https://dr2.nlm.nih.gov/  The National Institute of Environmental Health Sciences (NIEHS) and the National Library of Medicine (NLM) host the DR2 site which now includes a list of COVID-19 surveys and the domains assessed in the surveys. In addition to this COVID-19 list, DR2 provides a wide array of data collection tools and resources used in other public health emergencies and disasters, providing researchers with a rich repository of survey and other measurement tools that are applicable to the COVID-19 pandemic.