Socio/Clinical Findings about COVID-19 and Down Syndrome from Extant Research

Matthew P. Janicki, Ph.D.
University of Illinois at Chicago *and* the National Task Group on Intellectual Disabilities and Dementia Practices
mjanicki@uic.edu

- Presentation as part of a panel on '*COVID-19 and Down Syndrome*'
- Down Syndrome Affiliates in Action – February 20, 2021 – Virtual Conference

Acknowledgement

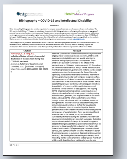
- The development of this presentation was supported by a grant from the Centers for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion, the Healthy Brain Initiative Award #1 NU58DP006782-01-00, to the University of Illinois at Chicago. The contents are solely the responsibility of the author and do not represent the official views of CDC.
- No conflicts of interest

Speaker Background

- *Research Associate Professor*, Department of Disability and Human Development, University of Illinois at Chicago
- *Co-Chair*, National Task Group on Intellectual Disabilities and Dementia Practices
- *Member,* Federal Advisory Council on Alzheimer's Research, Care, and Services
- *Principal investigator*, Longitudinal study of specialized dementia-related care group homes designed for adults with intellectual disability
- *Formerly,* Director for Aging and Special Populations for the New York State Office for People with Developmental Disabilities

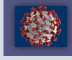
Aim and source of data

- To comment on the findings of a range of studies examining socio/clinical factors and observations related to people with Down syndrome impacted by COVID-19
- Data source is an extensive bibliographical listing of published and grey literature studies/resources dating from January 2020 to February 2021
- Bibliographic source: *"Bibliography – COVID-19 and Intellectual Disability"*
  - Sourced at: https://www.the-ntg.org/



Limitations –
- Studies have been conducted at various times over the past year
- Populations studied may or may not have contained persons with Down syndrome
- Findings were drawn from studies undertaken in a variety of countries

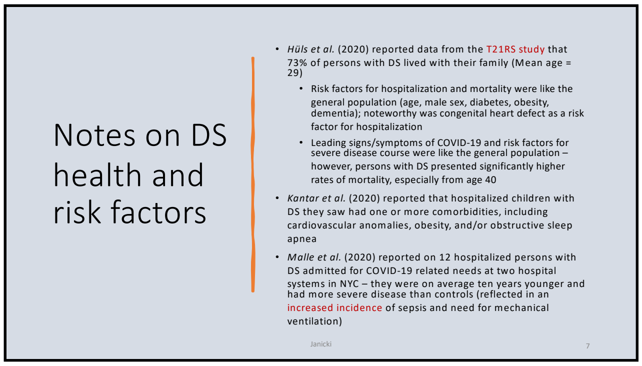
What were the major socio-political issues?



- **Visitation to those hospitalized**
  - Contention: Medical facilities refused access for visits due to concerns of the spread of COVID-19
  - *Settled: Federal policies enabled access for visitation by families, care staff, etc. for persons with an intellectual disability*
- **Prioritization for testing**
  - Contention: Agencies and families were experiencing difficulties with accessing COVID-19 testing for people with disabilities
  - *Settled: With greater awareness and availability of tests and testing sites, this barrier became less problematic*
- **Prioritization for inoculations**
  - Contention: CDC policies omitted persons with intellectual disabilities from the first wave of vaccinations (unless in long-term care/nursing facilities)
  - *Settled: Partially – CDC added adults with Down syndrome to the high-risk group eligible for early vaccination. Not settled yet is equity in access for other persons with intellectual disability*

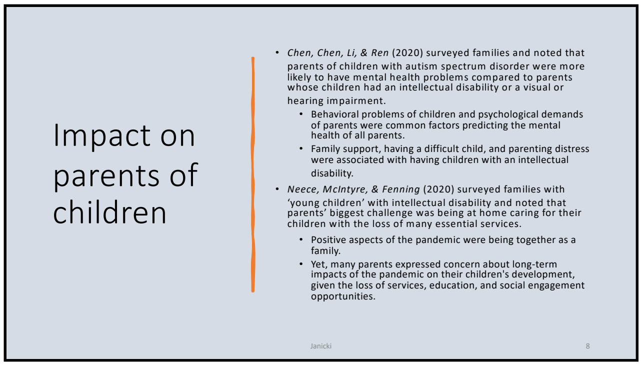
Most recent public policy issues

- *Gulati et al.* (2020) noted that adults with intellectual disability already experience substantial barriers to accessing medical care and are often more likely to be at increased risk of both the infection and of experiencing problems associated with accessing information, testing, and treatment
- *Hotez et al.* (2021) have raised the concern of the omission of adults with intellectual disability from the vaccination priorities and propose that all individuals with intellectual disability should be prioritized for vaccinations (which requires a broadening of current Phase 1 prioritizations.)
- *Hotez et al.* proposed that persons with intellectual disability 'should expressly be integrated into state vaccination guidelines and such guidelines should consistently include those in group homes or other settings, as well as their direct support professionals, and make procedures understandable and easy to navigate'
  - *The writers note that although the CDC guidelines were revised on December 23, 2020 to include persons with Down Syndrome, that revision does not account for all intellectual disabilities – which are far more prevalent*



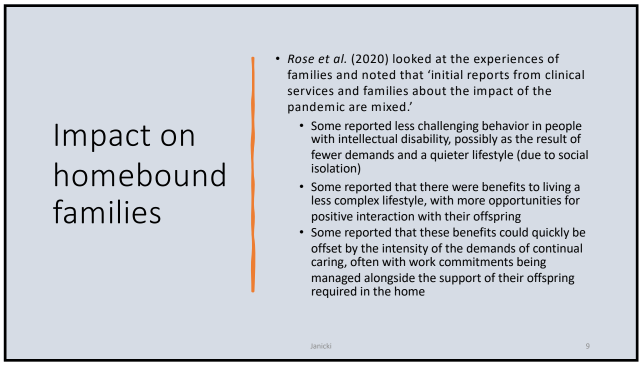
Notes on DS health and risk factors

- *Hüls et al.* (2020) reported data from the T21RS study that 73% of persons with DS lived with their family (Mean age = 29)
  - Risk factors for hospitalization and mortality were like the general population (age, male sex, diabetes, obesity, dementia); noteworthy was congenital heart defect as a risk factor for hospitalization
  - Leading signs/symptoms of COVID-19 and risk factors for severe disease course were like the general population – however, persons with DS presented significantly higher rates of mortality, especially from age 40
- *Kantar et al.* (2020) reported that hospitalized children with DS they saw had one or more comorbidities, including cardiovascular anomalies, obesity, and/or obstructive sleep apnea
- *Malle et al.* (2020) reported on 12 hospitalized persons with DS admitted for COVID-19 related needs at two hospital systems in NYC – they were on average ten years younger and had more severe disease than controls (reflected in an increased incidence of sepsis and need for mechanical ventilation)



Impact on parents of children

- *Chen, Chen, Li, & Ren* (2020) surveyed families and noted that parents of children with autism spectrum disorder were more likely to have mental health problems compared to parents whose children had an intellectual disability or a visual or hearing impairment.
  - Behavioral problems of children and psychological demands of parents were common factors predicting the mental health of all parents.
  - Family support, having a difficult child, and parenting distress were associated with having children with an intellectual disability.
- *Neece, McIntyre, & Fenning* (2020) surveyed families with ‘young children’ with intellectual disability and noted that parents’ biggest challenge was being at home caring for their children with the loss of many essential services.
  - Positive aspects of the pandemic were being together as a family.
  - Yet, many parents expressed concern about long-term impacts of the pandemic on their children's development, given the loss of services, education, and social engagement opportunities.



Impact on homebound families

- *Rose et al.* (2020) looked at the experiences of families and noted that ‘initial reports from clinical services and families about the impact of the pandemic are mixed.’
  - Some reported less challenging behavior in people with intellectual disability, possibly as the result of fewer demands and a quieter lifestyle (due to social isolation)
  - Some reported that there were benefits to living a less complex lifestyle, with more opportunities for positive interaction with their offspring
  - Some reported that these benefits could quickly be offset by the intensity of the demands of continual caring, often with work commitments being managed alongside the support of their offspring required in the home

Impact on persons with ID/DS and families

- *SCPLD* (2020) undertook a national survey of people with intellectual disabilities and their parents, caregivers and supporters to explore the impact of the pandemic on them
- Noted were these common concerns:
    - Reduction or removal of support, increased social isolation (compounded by digital exclusion), and mental health issues were having an impact on people with intellectual disability
    - Increased pressure on family caregivers because of reductions in support from care providers or fears of accepting support due to the risks of COVID-19
    - Increased pressure on *paid* caregivers, due to staff shortages, and changes to how support is given
    - Expressed feelings of anxiety and uncertainty about how long isolation/mitigation measures would last, and whether their usual support and activities would return once these measures are lifted
- *Gulati et al.* (2020) noted that adults with intellectual disability may be particularly vulnerable to isolation and psychological distress arising from fears about personal familial infection and due to social distancing and quarantine measures

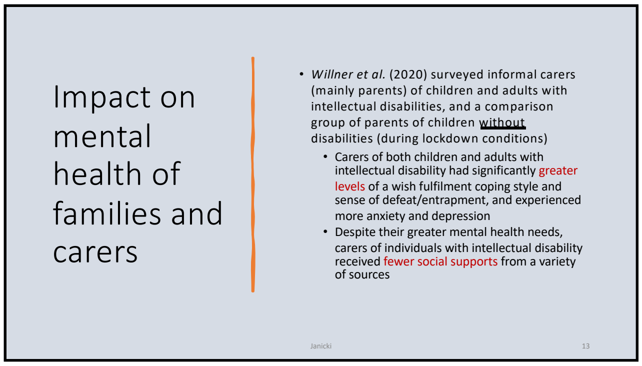
SCPLD = Scottish Commission for People with Learning Disabilities

Impact on caregiver siblings

- *Redquest, Tint, Ries, & Lunsky* (2021) studied the experiences of adult siblings of persons with intellectual disability and noted that most siblings were supporting their brother or sister with an intellectual disability during the COVID-19 pandemic but *had concerns* about their sibling's *health and well-being*
    - The most common concern related to disruption of their brother's or sister's routine and activities
    - Siblings noted that particularly helpful during the pandemic was their own self-care and relationships with others, as well as continuing support for their brother/sister

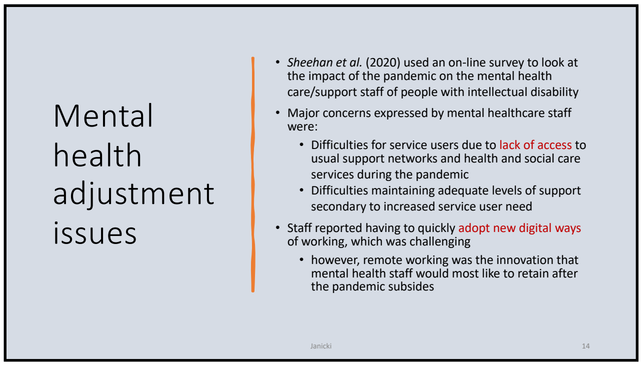
Mental health issues

- *Courtenay* (2020) noted that psychiatrists working with people with intellectual disability were seeing a *rise in requests for psychotropic medication* to help families and carers manage behaviors that are challenging to them
- *Eusebio* (2020) noted that the *loneliness* reported by many people with intellectual disability has been aggravated by quarantining, as lockdowns meant a sudden deprivation of specialized services and work opportunities – and concerns over rationing of care further increased worry and fear
- *Courtenay & Perera* (2020) noted that people with intellectual disability were *vulnerable to exploitation* by others when the usual community supports no longer functioned to protect them



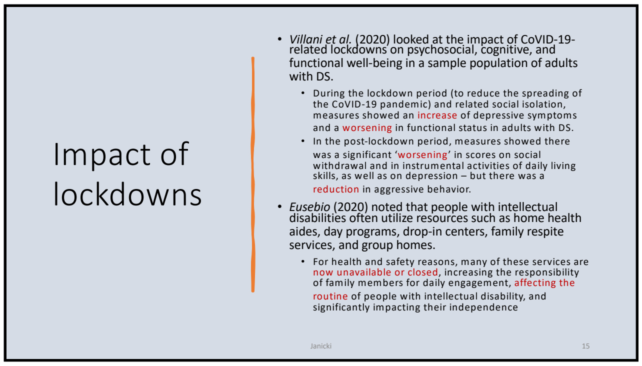
Impact on mental health of families and carers

- *Willner et al.* (2020) surveyed informal carers (mainly parents) of children and adults with intellectual disabilities, and a comparison group of parents of children without disabilities (during lockdown conditions)
  - Carers of both children and adults with intellectual disability had significantly greater levels of a wish fulfilment coping style and sense of defeat/entrapment, and experienced more anxiety and depression
  - Despite their greater mental health needs, carers of individuals with intellectual disability received fewer social supports from a variety of sources



Mental health adjustment issues

- *Sheehan et al.* (2020) used an on-line survey to look at the impact of the pandemic on the mental health care/support staff of people with intellectual disability
- Major concerns expressed by mental healthcare staff were:
  - Difficulties for service users due to lack of access to usual support networks and health and social care services during the pandemic
  - Difficulties maintaining adequate levels of support secondary to increased service user need
- Staff reported having to quickly adopt new digital ways of working, which was challenging
  - however, remote working was the innovation that mental health staff would most like to retain after the pandemic subsides



Impact of lockdowns

- *Villani et al.* (2020) looked at the impact of CoVID-19-related lockdowns on psychosocial, cognitive, and functional well-being in a sample population of adults with DS.
  - During the lockdown period (to reduce the spreading of the CoVID-19 pandemic) and related social isolation, measures showed an increase of depressive symptoms and a worsening in functional status in adults with DS.
  - In the post-lockdown period, measures showed there was a significant 'worsening' in scores on social withdrawal and in instrumental activities of daily living skills, as well as on depression – but there was a reduction in aggressive behavior.
- *Eusebio* (2020) noted that people with intellectual disabilities often utilize resources such as home health aides, day programs, drop-in centers, family respite services, and group homes.
  - For health and safety reasons, many of these services are now unavailable or closed, increasing the responsibility of family members for daily engagement, affecting the routine of people with intellectual disability, and significantly impacting their independence

Some findings particular to Down syndrome

- *del Carmen Ortega et al.* (2020) noted that lower infection rates detected *since September 2020*, in individuals with Down syndrome, might be partly explained 'by certain behavioral and cognitive traits, such as constancy, tenacity, and commitment to tasks that individuals have interiorized, which are not commonly reported in persons with other genetic syndromes associated with intellectual disability'
- They also noted that people with Down syndrome also share 'a tendency to imitate and repeat behavior that might lead to ritualization and perfectionism – and thus may offer greater compliance with mitigation efforts'

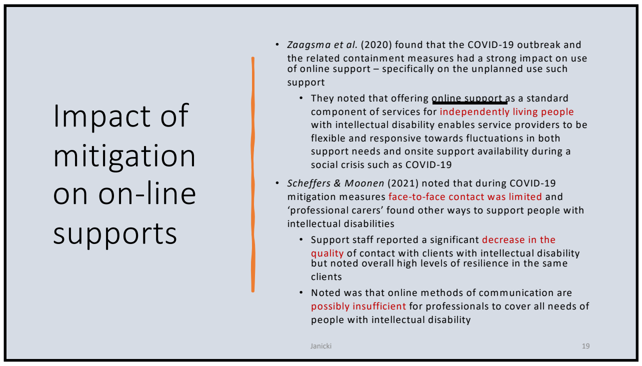
Dementia and COVID-19 risk

- *Wang, Davis, Gurney, & Xu* (2021) examined the morbidity and mortality rates of persons affected by dementia and infected by COVID-19 – although looking at the population in general some findings are useful for generalizing to Down syndrome and other intellectual disability
  - Adults with dementia are at significantly increased risk for COVID-19 and adverse outcomes
  - Risk for COVID-19 was highest among non-Alzheimer's disease associated dementias
  - Advanced age had no additional effect on the risk of getting COVID-19 among adults with dementia
  - Some adults with dementia may be particularly prone to COVID-19 infection because their impaired memory limits their ability to comply with social distancing, mask wearing, or hand washing

Dementia was defined as including most etiologies (but not Lewy body and fronto-temporal)

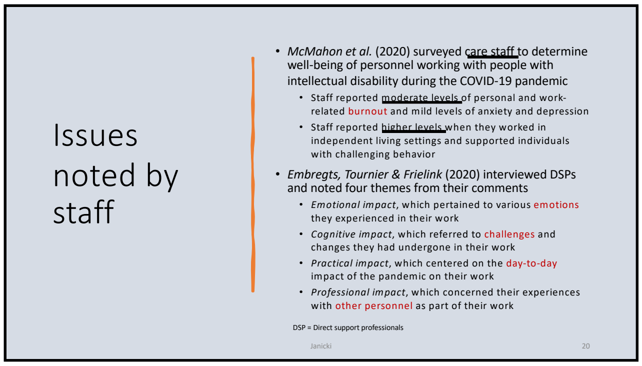
Impact on services - losses

- *Constantino et al.* (2020) noted that suspension of classroom time disproportionately affected children with intellectual disability, who often require special educational services, increased teacher-student ratios, and specialized interventions – many of which need to be administered in person
- *Constantino et al.* (2020) also noted that people with intellectual disability often cannot verbalize their symptoms during telemedicine appointments, and physicians need to use their best judgement in providing in-person care for them when necessary
- *Jeste et al.* (2020) surveyed families and found that most families reported a loss of at least some educational or healthcare services
  - 74% of parents reported that their child lost access to at least one therapy or education service, 36% lost access to a healthcare provider, and 56% said their child received at least some continued services through tele-education.
  - Those families that needed to access healthcare providers did so primarily through telemedicine



Impact of mitigation on on-line supports

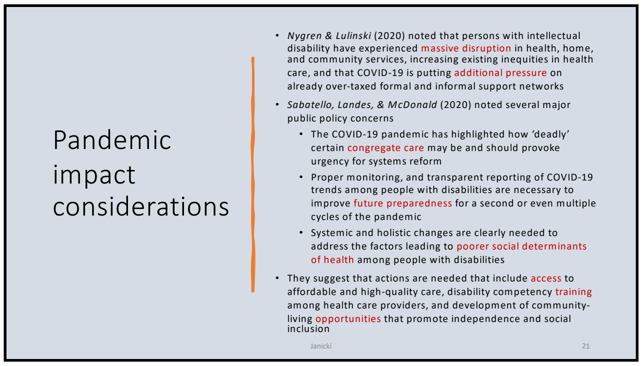
- *Zaagsma et al.* (2020) found that the COVID-19 outbreak and the related containment measures had a strong impact on use of online support – specifically on the unplanned use such support
  - They noted that offering online support as a standard component of services for independently living people with intellectual disability enables service providers to be flexible and responsive towards fluctuations in both support needs and onsite support availability during a social crisis such as COVID-19
- *Scheffers & Moonen* (2021) noted that during COVID-19 mitigation measures face-to-face contact was limited and 'professional carers' found other ways to support people with intellectual disabilities
  - Support staff reported a significant decrease in the quality of contact with clients with intellectual disability but noted overall high levels of resilience in the same clients
  - Noted was that online methods of communication are possibly insufficient for professionals to cover all needs of people with intellectual disability



Issues noted by staff

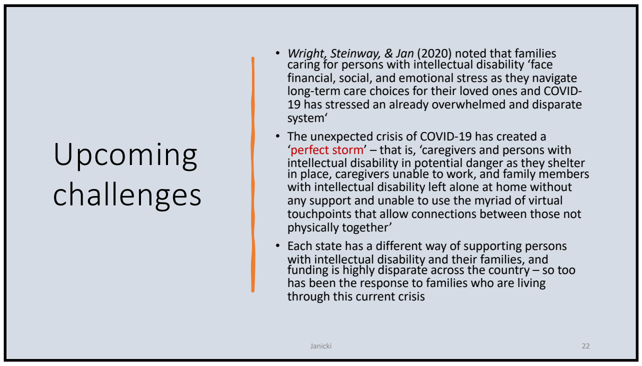
- *McMahon et al.* (2020) surveyed care staff to determine well-being of personnel working with people with intellectual disability during the COVID-19 pandemic
  - Staff reported moderate levels of personal and work-related burnout and mild levels of anxiety and depression
  - Staff reported higher levels when they worked in independent living settings and supported individuals with challenging behavior
- *Embregts, Tournier & Frielink* (2020) interviewed DSPs and noted four themes from their comments
  - *Emotional impact*, which pertained to various emotions they experienced in their work
  - *Cognitive impact*, which referred to challenges and changes they had undergone in their work
  - *Practical impact*, which centered on the day-to-day impact of the pandemic on their work
  - *Professional impact*, which concerned their experiences with other personnel as part of their work

DSP = Direct support professionals



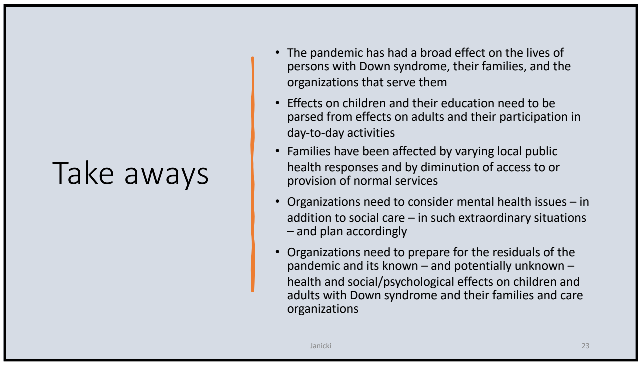
Pandemic impact considerations

- *Nygren & Lulinski* (2020) noted that persons with intellectual disability have experienced massive disruption in health, home, and community services, increasing existing inequities in health care, and that COVID-19 is putting additional pressure on already over-taxed formal and informal support networks
- *Sabatello, Landes, & McDonald* (2020) noted several major public policy concerns
  - The COVID-19 pandemic has highlighted how 'deadly' certain congregate care may be and should provoke urgency for systems reform
  - Proper monitoring, and transparent reporting of COVID-19 trends among people with disabilities are necessary to improve future preparedness for a second or even multiple cycles of the pandemic
  - Systemic and holistic changes are clearly needed to address the factors leading to poorer social determinants of health among people with disabilities
- They suggest that actions are needed that include access to affordable and high-quality care, disability competency training among health care providers, and development of community-living opportunities that promote independence and social inclusion



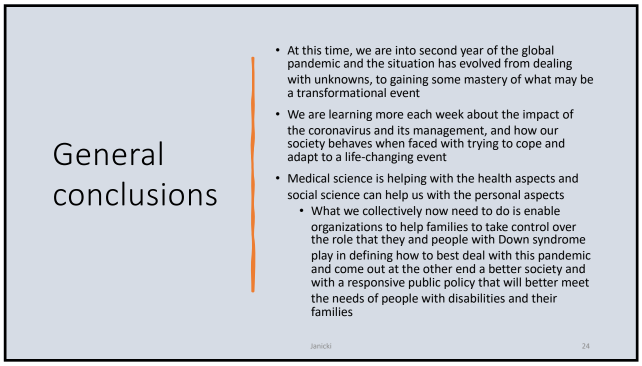
Upcoming challenges

- *Wright, Steinway, & Jan* (2020) noted that families caring for persons with intellectual disability 'face financial, social, and emotional stress as they navigate long-term care choices for their loved ones and COVID-19 has stressed an already overwhelmed and disparate system'
- The unexpected crisis of COVID-19 has created a 'perfect storm' – that is, 'caregivers and persons with intellectual disability in potential danger as they shelter in place, caregivers unable to work, and family members with intellectual disability left alone at home without any support and unable to use the myriad of virtual touchpoints that allow connections between those not physically together'
- Each state has a different way of supporting persons with intellectual disability and their families, and funding is highly disparate across the country – so too has been the response to families who are living through this current crisis



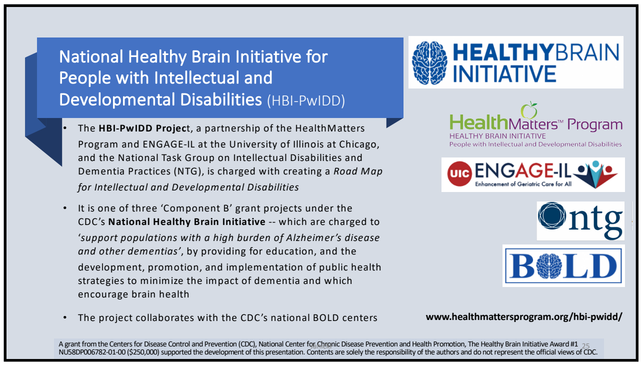
Take aways

- The pandemic has had a broad effect on the lives of persons with Down syndrome, their families, and the organizations that serve them
- Effects on children and their education need to be parsed from effects on adults and their participation in day-to-day activities
- Families have been affected by varying local public health responses and by diminution of access to or provision of normal services
- Organizations need to consider mental health issues – in addition to social care – in such extraordinary situations – and plan accordingly
- Organizations need to prepare for the residuals of the pandemic and its known – and potentially unknown – health and social/psychological effects on children and adults with Down syndrome and their families and care organizations



General conclusions

- At this time, we are into second year of the global pandemic and the situation has evolved from dealing with unknowns, to gaining some mastery of what may be a transformational event
- We are learning more each week about the impact of the coronavirus and its management, and how our society behaves when faced with trying to cope and adapt to a life-changing event
- Medical science is helping with the health aspects and social science can help us with the personal aspects
  - What we collectively now need to do is enable organizations to help families to take control over the role that they and people with Down syndrome play in defining how to best deal with this pandemic and come out at the other end a better society and with a responsive public policy that will better meet the needs of people with disabilities and their families

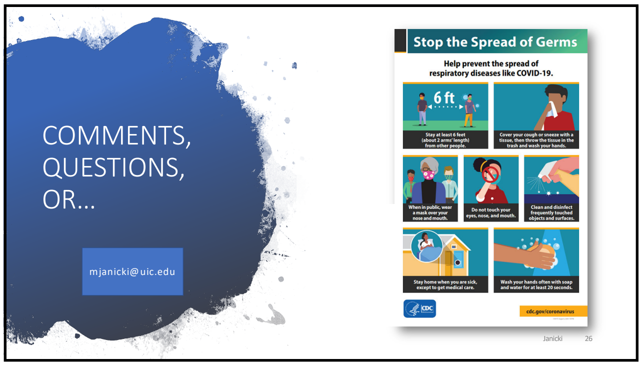


National Healthy Brain Initiative for People with Intellectual and Developmental Disabilities (HBI-PwIDD)

- The **HBI-PwIDD Project**, a partnership of the HealthMatters Program and ENGAGE-IL at the University of Illinois at Chicago, and the National Task Group on Intellectual Disabilities and Dementia Practices (NTG), is charged with creating a *Road Map for Intellectual and Developmental Disabilities*
- It is one of three 'Component B' grant projects under the CDC's **National Healthy Brain Initiative** -- which are charged to *'support populations with a high burden of Alzheimer's disease and other dementias'*, by providing for education, and the development, promotion, and implementation of public health strategies to minimize the impact of dementia and which encourage brain health
- The project collaborates with the CDC's national BOLD centers

www.healthmattersprogram.org/hbi-pwidd/

A grant from the Centers for Disease Control and Prevention (CDC), National Center for Chronic Disease Prevention and Health Promotion, The Healthy Brain Initiative Award #1 NU58DP006782-01-00 ($250,000) supported the development of this presentation. Contents are solely the responsibility of the authors and do not represent the official views of CDC.



COMMENTS, QUESTIONS, OR…

mjanicki@uic.edu

Stop the Spread of Germs

Help prevent the spread of respiratory diseases like COVID-19.

- Stay at least 6 feet (about 2 arms' length) from other people.
- Cover your cough or sneeze with a tissue, then throw the tissue in the trash and wash your hands.
- When in public, wear a mask over your nose and mouth.
- Do not touch your eyes, nose, and mouth.
- Clean and disinfect frequently touched objects and surfaces.
- Stay home when you are sick, except to get medical care.
- Wash your hands often with soap and water for at least 20 seconds.

cdc.gov/coronavirus