Communicating with PWD/IDD (evidence-based)

- PWD and IDD often need longer to express self and respond (may say "I don't know" when they really mean "I am scared or need more time or I am not sure how to tell you my symptoms")

- Use short simple phrases & speak slowly and clearly

- Pointing to symptoms may be more helpful than expressing them

- In COVID-19 Hypo-Delirium in early studies-common (**A Bianchetti, 2020**)

- **ALL behavior has meaning** with dementia and IDD so do not cover it up!

- Be aware of nonverbal communications BOTH WAYS-your stress leads-increased behavioral symptoms-vocalizations, restlessness, sadness, resistance to care. Use tone of voice, eyes, & smiling behind mask as tools

- Simulated family presence 1 minute video-in an RCT (**Waszynski, 2018**)

- Many with IDD and dementia rely on touch as a de-escalation, communication and comfort tool. How can we simulate that?

The Epidemic Within the Pandemic: Delirium

Delirium is leaving many older patients more vulnerable. They need caregivers, despite no-visitor rules.

By Sharon K. Inouye

Dr. Inouye is a geriatrician and founder of the Hospital Elder Life Program.

May 10, 2020, 11:00 a.m. ET

"THINK DELIRIUM"/Assess Delirium

ATYPICAL PRESENTATIONS in older adults, PWD and IDD

- Pneumonia
- MI/Congestive Heart failure
- COVID-19
- Infection/SEPSIS
- Depression
- Adverse Drug reaction
- Dehydration
- DELIRIUM MEASURES NIDUS
  https://deliriumnetwork.org/measurement/delirium-info-cards/

DELIRIUM
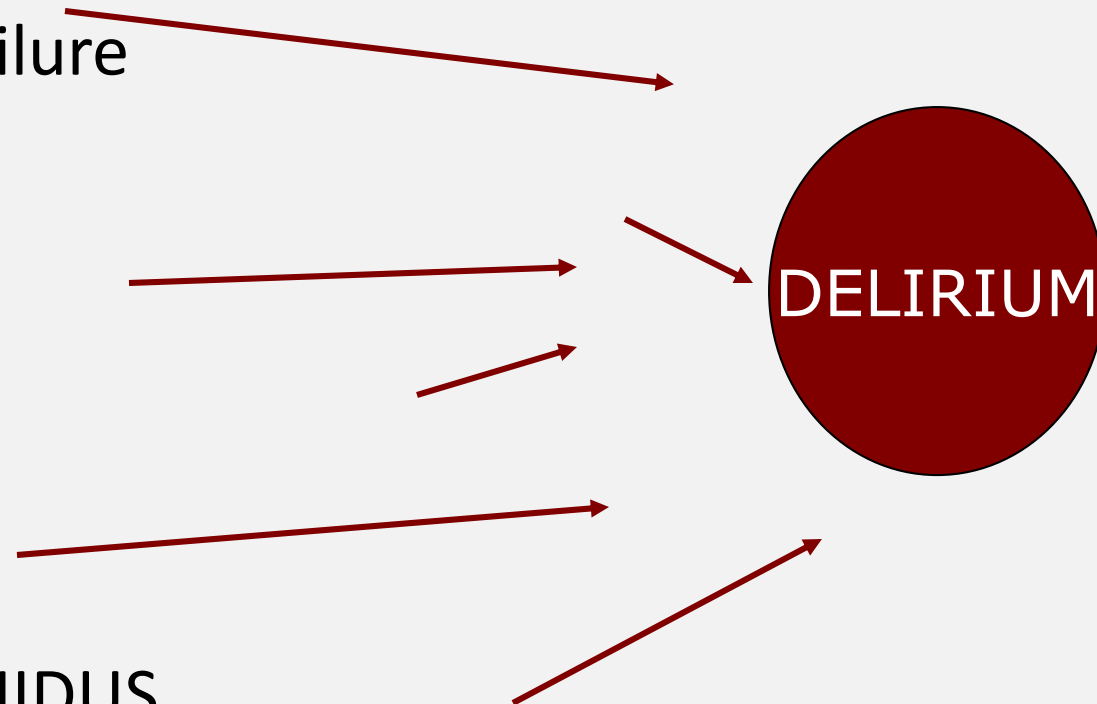
Positive Points of Light/What We Can Do NOW

- Use creative tools such as Adapted Go Bag for home, familiar thing/photo pillow, What Matters & All About Me Board across settings of care, apps

- TECHNOLOGY CAN WORK with adaption/facilitator with both IDD and PWD

- Music and Arts/Harmony Penn State/Best Buddies International/Timeslips-https://www.bestbuddies.org/   https://www.timeslips.org/

- Need care partners at bedside-ESSENTIAL expert, de-escalation, power of touch, knows them best, recognize delirium and we need to provide information.

- Gradually introduce tools to re-enter public. Use visuals for-wearing mask, distancing, fear

- Provide Caregiver support AND Information-suddenly no respite, working from home https://www.nia.nih.gov/health/government-covid-19-resources-older-adults http://www.ihi.org/Topics/COVID-19/Pages/COVID-19-Care-of-Older-Adults.aspx

- **NEED more RESEARCH funding for communication, tools for technology in IDD, support, caregiving, decision-making, short and long-term impact, policies.**

TODAY IS

_____, _____ ___, ____

ALL ABOUT ME

I worked as a

What matters most to me is

I am from

I matter too

MY NAME IS
_____

I PREFER TO BE CALLED

Things that make me feel happy are

I have hearing/vision impairment & have glasses/hearing aides

I feel relaxed and calm when

I communicate best BY

My goals are

I don't like

YOUR NURSE TODAY IS:

YOUR NURSING ASSISTANT TODAY IS:

_____

_____

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Observations from Direct Service Professionals

- **Technology has allowed MANY to participate that have not been able**

- Make link easy to find or write down for them, email right before

- ZOOM accessibility hearing/vision impaired

- Need a facilitator for those with moderate to severe disabilities

- Ideas to improve mobility & social isolation-ZOOM dance party, sing alongs, virtual theatre, games, movie night

- Have break out groups

- **NEED MORE RESEARCH on DSPs and COVID**

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Resources and References IDD & PWD

COVID resources NIH & Institute for Healthcare Improvement

https://www.nia.nih.gov/health/government-covid-19-resources-older-adults
http://www.ihi.org/Topics/COVID-19/Pages/COVID-19-Care-of-Older-Adults.aspx

National Down Syndrome Association & Collaborative for COVID resources
https://www.ndss.org/ndss-covid-19-down-syndrome-resource/

Alzheimer's Association Caregiver tips https://www.alz.org/help-support/caregiving/coronavirus-(covid-19)-tips-for-dementia-care

Nursing Home Toolkit for positive behavioral health https://www.alz.org/help-support/caregiving/coronavirus-(covid-19)-tips-for-dementia-care

AMDA Guidance PA-LTC https://paltc.org/COVID-19

World Institute on Disability https://wid.org/

Communicating with and about persons with disabilities
https://www.dol.gov/odep/pubs/fact/communicating.htm