

Notes from Vaccine Panel

Vaccine Distribution and Prioritization

- COVID19 Vaccine workgroup- propose recommendations for the Advisory Committee for Immunization Practices
- Ethical principles applied to decision-making on vaccine distribution and prioritization:
 - Minimize harm, maximize benefits
 - Mitigate health disparities
 - Promote justice
 - Promote transparency
- Developmental disabilities included as a part of long-term care in vaccine prioritization
- Not everyone with IDD is in a long-term care facility, so difficult to figure out prioritization
- Reports show a lot of vaccine hesitancy
 - not enough information about the vaccines because of how quick the vaccine was approved
 - novel instrument for vaccine delivery
 - wait and see what the reaction is, concerned about side-effects
 - atrocities from our history causing mistrust

UCEDD Efforts

- Creating vaccine knowledge in accessible formats
- Equitable vaccine distribution- created a taskforce that contribute to allocation decisions, struggle to get to equity instead of equality
 - decision-making around one metric
 - eg. age limits or risk of exposure
 - Consider multiple metrics to develop prioritization would be more equitable
- Partnering with DD network partners, but also remember people who aren't formally attached to these systems
- Continuing education to address hesitancy
- Address emerging needs: Eg. Increase use of restraint- develop guidance and listen to stakeholders to work to reduce or eliminate restraints in vaccine distribution
- Technical assistance to make distribution efforts accessible
- Information dissemination with community and across network.
- Most state guidance does not align with the CDC framework- UCEDDs could provide advocacy training specific to your state

Concerns and Issues raised by Self Advocates

1. When will self-advocates be eligible for vaccine?
2. Accessible information about COVID 19
 - a. Keeping up with all the changes and written so everyone can understand
3. How will guardianship and other issues around consent be handled when registering for vaccine?

4. Confusion regarding
 - a. getting tested versus getting the vaccine
 - b. test results (positive results mean you have the virus, not that you're all good)
5. Why are staff getting vaccine before some people with disabilities?
6. Combatting misinformation; we need clear information based on science
7. Many steps to be safe and do COVID mitigation
8. Emotional support to deal with friends who are dying
9. Supporting people who are afraid of shots

Actions by Self-Advocacy Movement and Recommendations for Future Action

- SARTAC has meetings about the vaccine with leaders across the country
- Plain Language booklet about COVID vaccine
- Plain language of public health information
- Informal sessions run by people with IDD for people with IDD to ask questions
- Work as partners with self-advocacy organizations in your state

Resources shared

Here are the latest COVID resources from the Center for Dignity in Healthcare for People with Disabilities. Newly published today is a plain-language FAQ about the vaccine:

<https://www.ucucedd.org/center-for-dignity-in-healthcare-for-people-with-disabilities/>

SARTAC's Plain Language Booklet on COVID Vaccines:

<https://selfadvocacyinfo.org/resource/covid-19-vaccine-information-in-plain-language/>

SARTAC: selfadvocacyinfo.org