

State DD Council COVID Vaccine Survey #2 Preliminary Results

February 2021

Methodology: This is the second survey on vaccine response. NACDD 15 state councils on developmental disabilities responded to online survey taken January - February 2021. For more information contact Erin Prangley at erin.prangley@nacdd.org.

Key Findings

- Prioritizing for I/DD in state vaccine distribution plans is happening in some states, but more needs to be done. Slightly more than half of state councils reported prioritizing (a,b,or c) for I/DD.
- Only half of respondents reported that the state's vaccine plan was shared broadly with people with I/DD. One-third of respondents strongly disagreed that information was being shared.
- Distribution remains a huge problem. Sixty-seven percent reporting that people do not know where to get the vaccine. Lack of transportation to vaccine sites remains an obstacle (53%). One third of states reported problems with 1) no clear instructions on second dose/follow up in plain language. And we are still having problems with support staff not being allowed to accompany people to vaccines in 2 states.

Key Findings

- Only half of states are creating databases of people with I/DD who receive their first dose (53%) with a slight drop off for second dose (47%). Less than one-third of states are following up with people about side effects (27%).
- Sixty-percent of councils reported that individuals with I/DD, families and caregivers are not getting information on when, where, and how people with I/DD will get their vaccines.
- One-quarter of councils have concerns about states, families, guardians obtaining consent from people with I/DD about vaccines.
- Forty-percent of the state councils reported reluctance from DSPs in their states to get the vaccine.

Key Findings

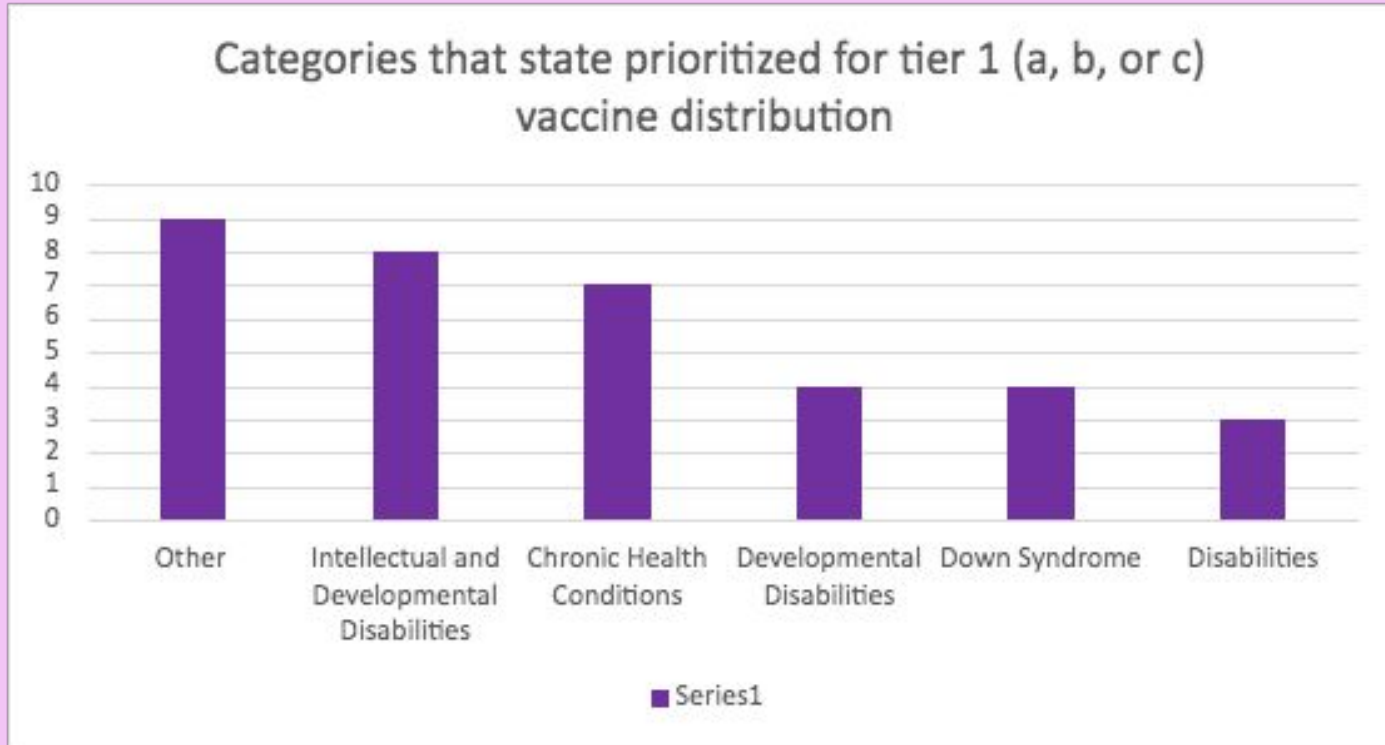
- Eighty-percent of councils are sharing state's vaccine plain with people with I/DD.
- Overwhelmingly, councils are taking an active role in following up with people with I/DD to see how they respond to vaccine. Ninety-three percent plan follow up activities for people with I/DD who receive the vaccine. Activities include: Collecting info reported to council (80%) and polling council members about their experiences (53%). Three councils are doing formal surveys and three councils are holding webinars/town halls to gather info.



01

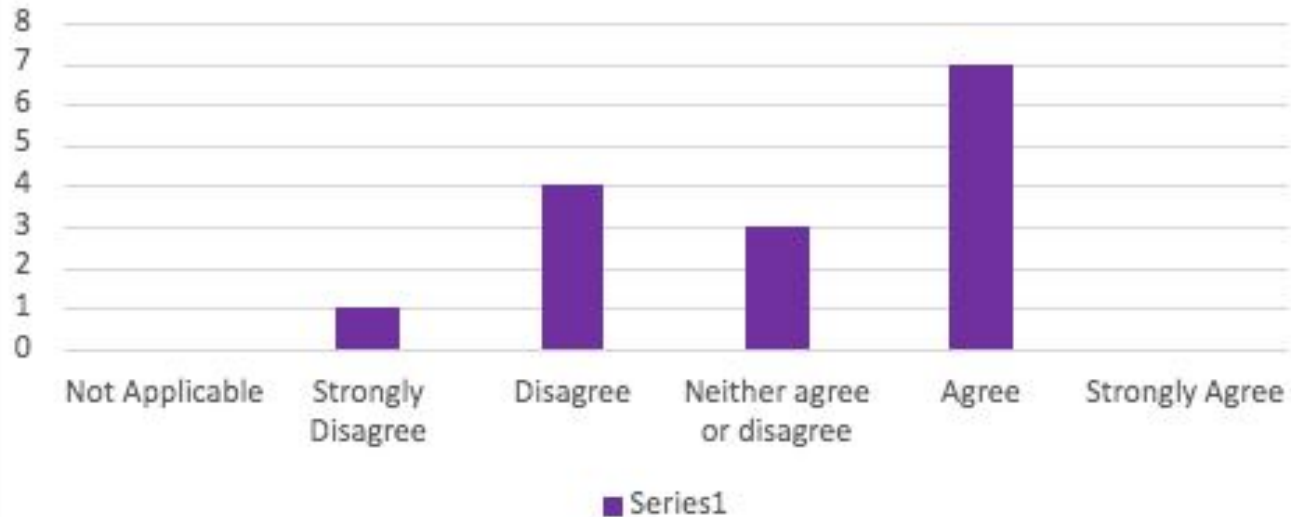
Vaccine Distribution

State Prioritization for Vaccine Distribution

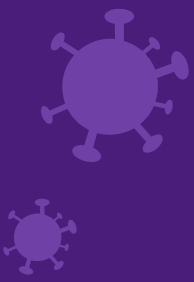


Vaccine Plan Sharing

Your state's vaccine plan is being shared broadly with people with I/DD throughout your state or territory



Comments



“Efforts are being publicized and information is available through multiple sources but it is difficult to measure the rate of success in reaching people.” - Massachusetts

“The disability community is having difficulty discerning where they fit among the priority groups. The categories are unclear.” - Virginia

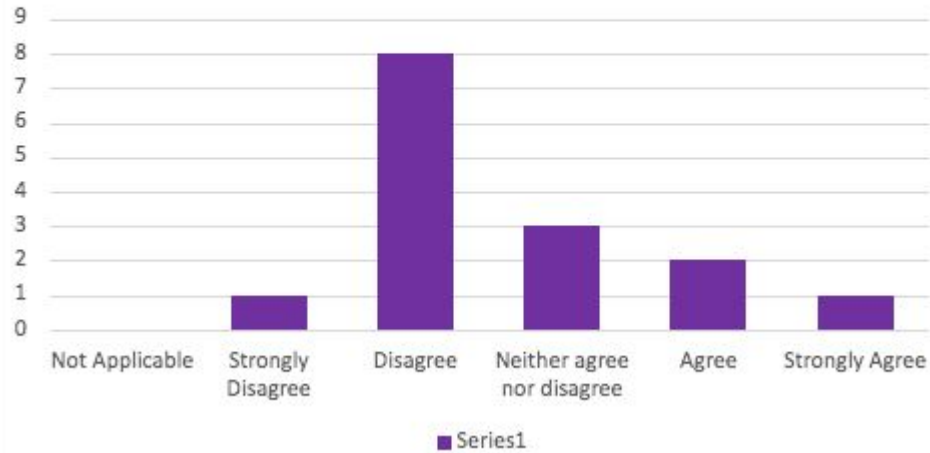


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Information and Consent Forms

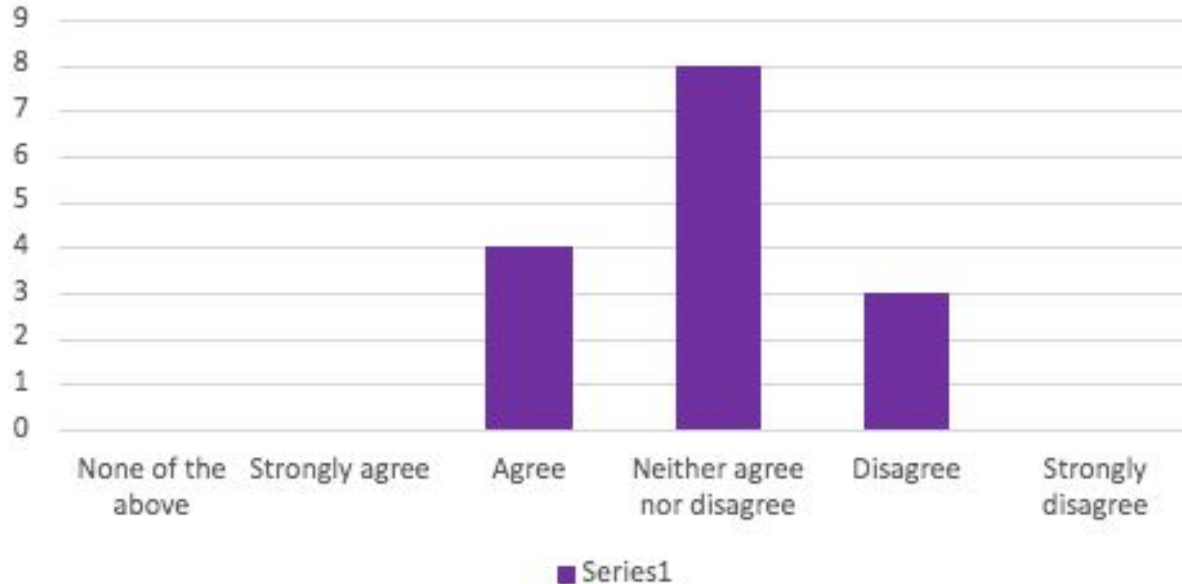
Vaccine Information

Individuals with I/DD, their families, and caregivers are getting information for when, where, and how people with I/DD will get their vaccines.



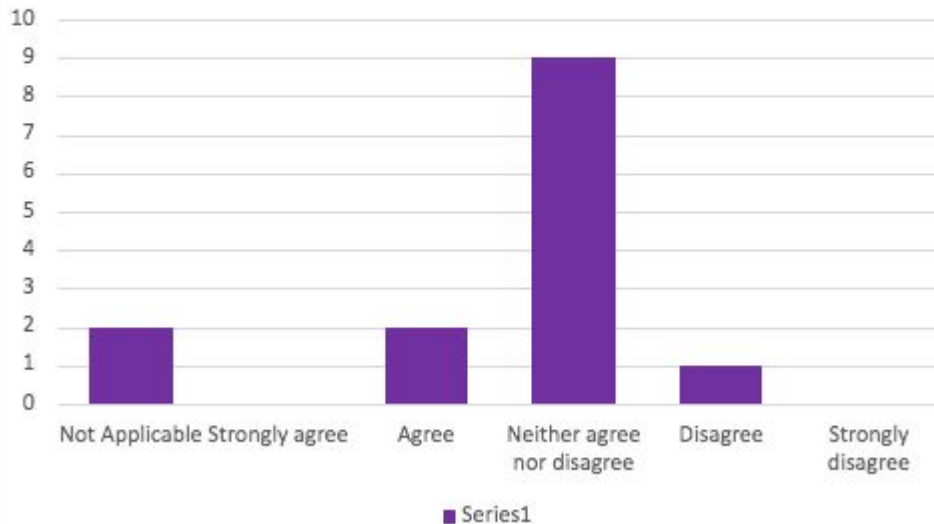
Consent Form Concerns

There were concerns from people with I/DD, family members or guardians about signing a consent form.



Consent Form Plain Language

The consent form was explained to the individual with I/DD in a way that they could understand and/or was there a plain language version offered.

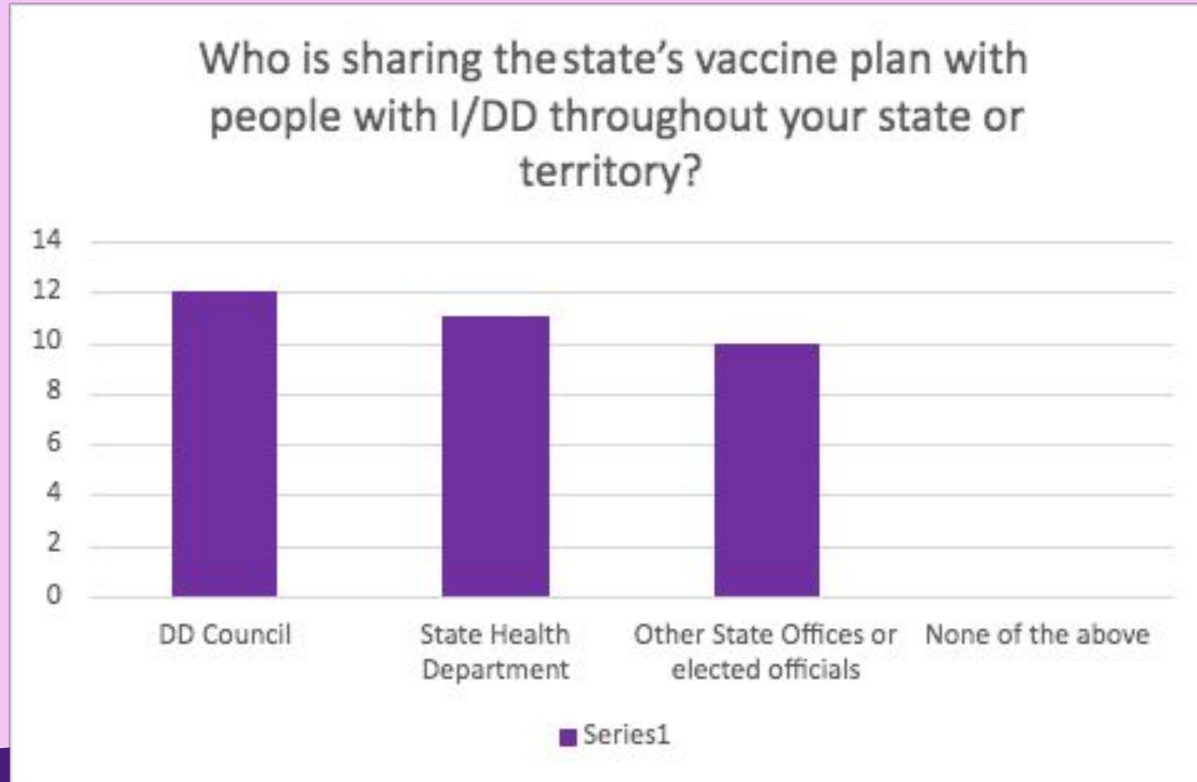




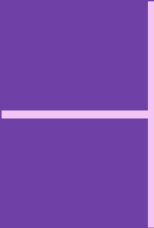
03

State Plans

Sharing State Vaccine Plan



Qualitative Comments

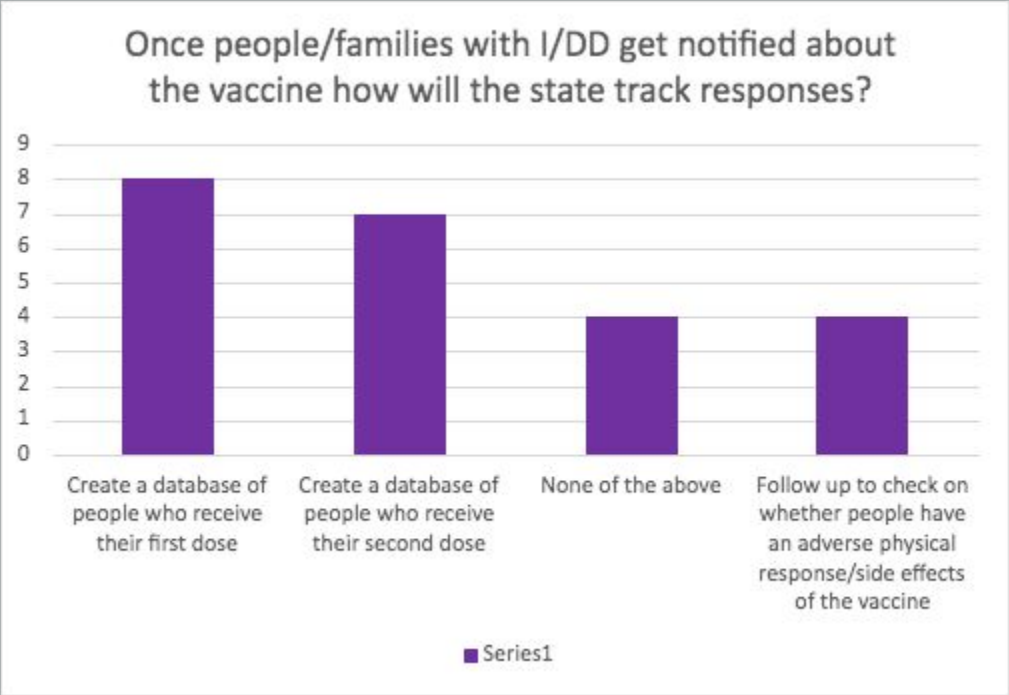


DD Coalition - providers,
self-advocacy groups, The Arc


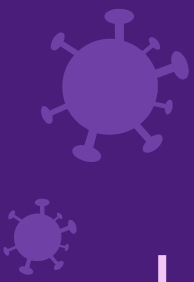


Department of Health Services
Medicaid Division

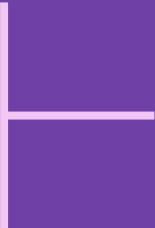
State Vaccine Tracking



Qualitative Comments



“The system is flawed. Those paid family caregivers who are eligible cannot locate an appt for a second dose.” - Arizona



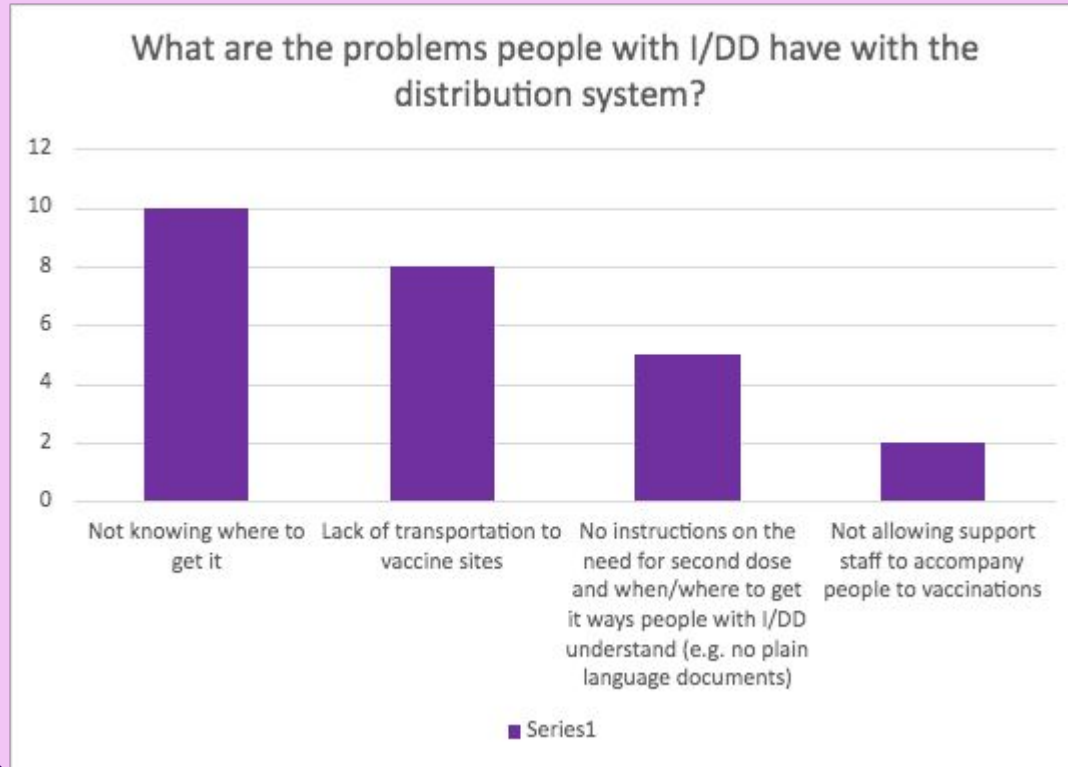
“Current system not working well to schedule. State Health Division (DHEC) is making their own and not rolled out yet.”
- South Carolina






04

Distribution Problems


Distribution System Problems



Qualitative Comments



“Not knowing who to contact; being told they are not in a priority group by local health dept. when they actually ARE in a priority group; being given dates/times for appointments that are expired (like telling people to go to a Monday appointment on Tuesday).” - Wisconsin



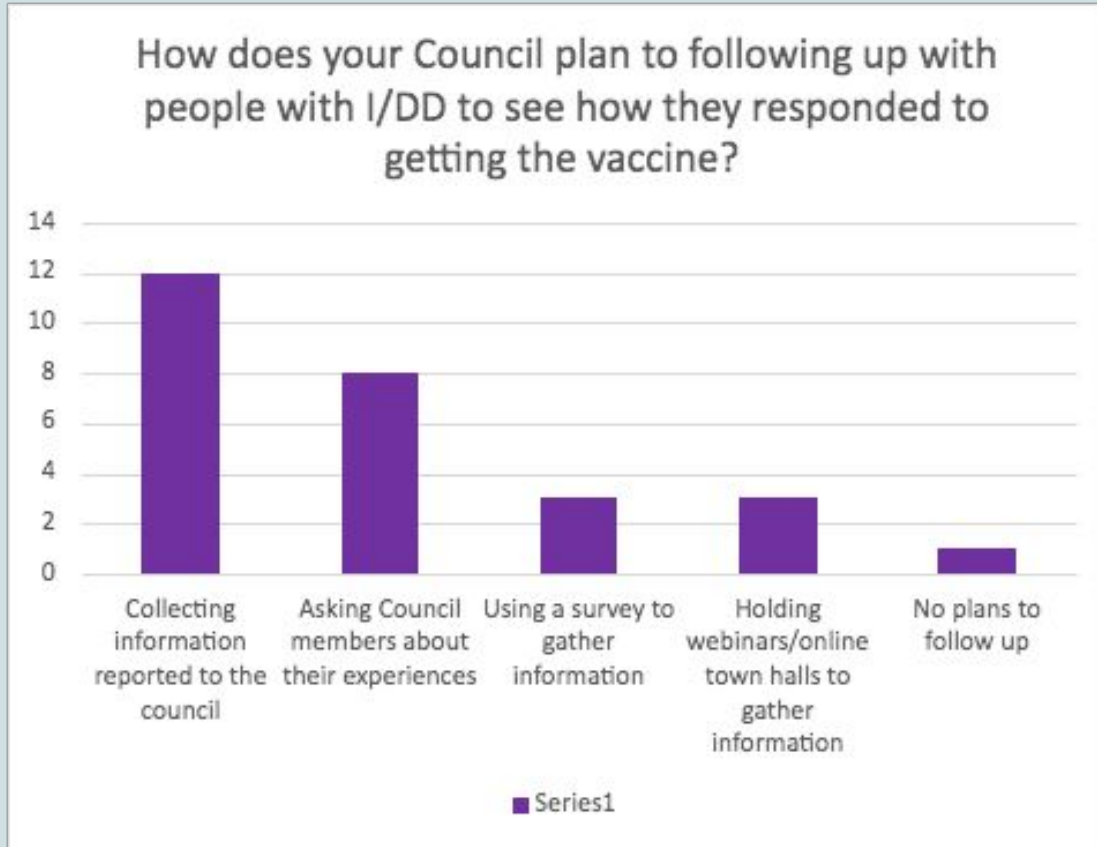
“Not prioritizing individuals with IDD and their caregivers who live in the community.” - New York



05

Council Follow-up

Follow-up Plans





06

Direct Service Providers

Direct Service Providers and Vaccines

Direct Service Providers (DSPs) in your state/territory are reluctant to get the vaccine

