

# COVID-19 Vaccines for Children with Developmental Disabilities: Survey of New York State Parents' Willingness and Concerns

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**ABSTRACT:** *Objective:* While 1 in 6 US children have a developmental disability (DD), and such children are disproportionately affected by COVID-19, little is known about their vaccination status. We surveyed New York State parents of children with DDs to ascertain willingness and concerns regarding COVID-19 vaccines. *Methods:* An online survey was distributed to statewide DD networks from June to September 2021 (vaccines were authorized for adolescents in May 2021). We report associations between vaccine willingness and concerns and race/ethnicity, child age, in-person schooling, routine/flu vaccinations, and DD diagnoses. Willingness was categorized as “got/will get ASAP” (high), “wait and see/only if required,” or “definitely not.” *Results:* A total of 352 parents (49.1% White) responded. Willingness differed by age ( $p < 0.001$ ). High willingness was reported for 73.9%, 50.0%, and 36.0% of children aged 12 to 17, 6 to 11, and 0 to 5 years, respectively. Willingness differed by autism diagnosis ( $p < 0.01$ ) and routine and flu vaccination status ( $p < 0.001$ ). Predominant concerns included side effects (89%) and children with disabilities not being in trials (80%). Less common concerns were COVID not serious enough in children to warrant vaccine (23%) and misinformation (e.g., microchips, 5G, DNA changes) (24%). Concerns about vaccine safety differed by age ( $p < 0.01$ ) and were highest for older and then the youngest children. In age-stratified adjusted models, attention-deficit/hyperactivity disorder was *negatively* associated with high willingness for age 5 or younger (OR = 0.02, 95% confidence interval, <0.001–0.622). *Conclusion:* Parents of children with DD in New York seemed highly willing for them to receive COVID-19 vaccines. Although few factors predicted willingness to vaccinate, addressing safety and developmental concerns regarding young children is warranted. Given their increased vulnerability, improved COVID-19 surveillance for children with DD is warranted.

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**S**ARS-CoV-2 (COVID-19) poses a heightened risk for individuals with intellectual and/or developmental

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disabilities (DD). “DD” includes disorders that begin in childhood; affect physical, social, and/or emotional development; and may affect multiple body parts or systems. They span conditions such as autism spectrum disorder, cerebral palsy, Down syndrome, hearing loss, and attention-deficit/hyperactivity disorder (ADHD). COVID-specific disparities in outcome vary within intellectual and developmental disabilities (IDD); intellectual disability (ID) is associated with higher infection and case-fatality rates in adults,<sup>1,2</sup> while DDs more generally increase the likelihood of hospitalization associated with COVID-19. For example, people with comorbid autism and ID were 9.3 times more likely to be hospitalized than people with COVID-19 without those diagnoses, while those with learning disabilities and autism (alone) were 3.8 and 3.6 times, respectively, more likely to be hospitalized than people without those diagnoses.<sup>3</sup> Furthermore, adults with disabilities are more likely to want—but less likely to receive—a COVID-19 vaccine, than their nondisabled peers, in part because of inaccessible systems.<sup>4</sup>

Approximately 1 in 6 children in the United States has a developmental disability.<sup>5</sup> Children with DD are

disproportionately affected by COVID because of medical conditions that increase risk of severe illness, difficulty practicing preventive behaviors (e.g., mask-wearing, social distancing), and limited access to accessible vaccine settings.<sup>6</sup> Amid the pandemic, children with DDs have experienced worsening anxiety, ADHD, and autism symptoms,<sup>7,8</sup> along with increased medication usage.<sup>9</sup> Given that children comprise 22% of the US population,<sup>10</sup> vaccine uptake in children is critical to protecting themselves and the community at large.<sup>11</sup> Although general (i.e., non-COVID-19) childhood vaccination rates in the United States have slowly increased in the past decade, current vaccination rates are impeded by COVID-19's impact on health care access and an ecosystem of generalized vaccine hesitancy.<sup>12</sup> Before the pandemic, children with ID were less likely to have completed recommended vaccinations,<sup>13,14</sup> as were children with autism (and their younger siblings).<sup>14</sup> Furthermore, even compared with parents of children with other chronic health or developmental conditions, parents of children with autism express more vaccine concerns.<sup>15</sup>

Pre-existing concern regarding approved vaccines also influence intention toward COVID-19 vaccines for children. Surveys from 2020 found that 60% to 70% of US parents expressed willingness for their child to receive a COVID-19 vaccine.<sup>16,17</sup> However, in an early 2021 survey of US parents, just 40% were willing to vaccinate. Willingness increased with child age, while unwillingness was linked to concerns about the vaccine being too new, side effects, and lasting health problems.<sup>18</sup> Among parents with children 12 years and younger, just 49% in a national sample would vaccinate their youngest child (median age = 4.7 years). Not having a child in school/daycare and living in the South or Midwest was associated with increased hesitance.<sup>19</sup> In this same survey with New York City parents, 62% would vaccinate their youngest child.<sup>20</sup> After the May 2021 emergency use authorization (EUA) of a vaccine for 12- to 15-year-olds in the United States,<sup>21</sup> the Kaiser Family Foundation's (KFF) Vaccine Monitor found increasing uptake and acceptance of vaccines for children. In September 2021, 52% of 12- to 17-year-olds had received the vaccine or would as soon as possible (ASAP) vs. 42% in both May and June 2021. Just 34% of parents of 5-11 year-olds, and 23% of parents of children younger than 5 years of age expressed willingness to vaccinate their child.<sup>22</sup> Finally, a representative sample of US parents from June 2021 found Black and Hispanic parents less willing to immediately vaccinate, while those with older children were more willing.<sup>23</sup>

Children become infected with, get sick from, and transmit COVID-19<sup>24</sup>; their rates of infection exceeded those of adults for the first time in August 2021.<sup>25</sup> Since the 2021-22 school year began, 1 in 4 children had to quarantine because of possible school-related exposures.<sup>22</sup> School closures, undertaken to reduce COVID-19 spread, adversely affect children's health and well-being.<sup>26</sup> Furthermore, although children with DDs are disproportionately affected by COVID-19, relatively little is known about

parents'/caregivers' willingness and concerns regarding COVID-19 vaccines for their children. Thus, we conducted an online survey of parents of children with DDs in New York State (NYS) during Summer-Fall 2021 to identify (1) willingness to vaccinate by demographic (i.e., diagnosis) and related risk factors (i.e., routine vaccination status), (2) vaccine-related concerns by child age, and (3) associations between risk factors and high willingness to vaccinate, stratified by child age.

## METHODS

### Survey Development

This survey was adapted from a prior study of COVID-19 vaccine perceptions and intentions among adults with IDD, their caregivers, and professionals who work with them.<sup>27</sup> For this parent/caregiver survey, many items were drawn directly from the above survey instrument, which included many from the Kaiser Family Foundation (KFF) surveys.<sup>28</sup> Additional items geared to parents/caregivers were informed by the literature and "Engage & Educate," a statewide campaign to promote vaccines among persons with DDs in New York State (NYS). These items included school/child care placement, preferred location for vaccination, and child-specific concerns about COVID-19 vaccines (e.g., effects on child development, fertility, interaction with required childhood vaccines). Data were analyzed by 3 age groups: (1) 12 to 17 years, i.e., adolescents, for whom there were emergency use authorizations (EUAs) at the time of the survey; (2) 6 to 11 years, i.e., school-age, who were the next age group up for EUA review; and (3) 5 years and younger, i.e., young children. After review by stakeholders, including parents, self-advocates, and disability service providers, the survey was translated into the following languages of the Engage & Educate project's community partners: Bengali, Chinese, Korean, and Spanish. This project received a determination of "Non-Research" from the institutional review boards at both sites.

### Survey Distribution

The survey was built into Research Electronic Data Capture, a user-friendly, Health Insurance Portability and Accountability Act (HIPAA)-compliant data capture system. In addition to the above languages, the survey was translated into American Sign Language (ASL). For the ASL version, all instructions and survey items were video recorded in ASL and then attached to each individual question. An electronic link with a plain language description of the survey in all languages was posted through national, statewide, and regional networks and social media channels from June 3 to September 21, 2021. The 3 University Centers of Excellence in Developmental Disabilities in NYS also disseminated the survey to their networks, which included local health departments, service providers, Special Olympics New York, school districts, and a 150-member consortium of

congregate care providers. Organizations serving persons with IDD who are Hispanic/Latino, Chinese, Korean, and South Asian also distributed the survey. Within NYS, the survey was shared using listservs and social media pages specific to parents of children with disabilities (e.g., parent advisory groups, parent leadership cohorts, special education parent-teacher associations).

## Survey Items

### Demographics and Placement Preferences

Individuals self-selected into the survey by indicating that they were a “caregiver who makes medical decisions for a child (under age 18) with a developmental disability” and were asked to complete the survey regarding one such index child. Participants reported on basic demographic information about their children including age band (i.e., 12–17 years, 6–11, 5 or younger), diagnoses provided, child hearing status, race and ethnicity, whether the child is up to date for current vaccines (including flu vaccine), and state of residence. Both (1) *current* school/child care placement and (2) *preferred* school/child care placement modality *for fall* were assessed with the following options: School: “100% in-person,” “100% remote” or “hybrid,” or; Child Care: “own home by someone else,” “other’s home,” “center-based,” or; “homeschooled.”

### Vaccine Willingness

Willingness to receive the COVID-19 vaccine was assessed with the following KFF item (additional instructions from the current survey italicized): “*For your child aged [12–17, 6–11, 5 or younger]:* How likely would you be to get the COVID-19 vaccine if it were offered for free?” Response options included the following: “already got (shown only for children aged 12–17),” “will get as soon as possible,” “wait and see,” “only if required,” and “definitely not.” We combined the first 2 responses into a “got/get ASAP” (i.e., “highly willing”) category. The next 2 categories were combined into a “waiting/if required” (i.e., “not yet willing”) category. Respondents who fell within either the final “do not intend” or “waiting/if required” category were shown an additional set of questions related to concerns about the vaccines.

### Vaccine Concerns

Those who did not report high intention around the vaccine were asked to rate potential reasons for concern as a “big reason,” “little reason,” or “not a reason.” Concerns were grouped into overarching themes: general COVID concerns and specific child/family concerns about the vaccine, age-related concerns (for children aged 5 and younger only, including that the child is too young and the child is already getting too many vaccines at their age), and general concerns about vaccines. An open-ended prompt asked parents to describe other reasons for concern.

### Preferred Vaccine Location

Parents were asked to rank order where they would prefer their child to be vaccinated for COVID-19, including office of pediatrician or family doctor, public

vaccination site, grocery store, child’s school, mobile vaccine unit, drive-through site, in-home service, and faith institution.

## Analysis

Descriptive analysis was performed on parent and child demographics and COVID-19 vaccine-related items. Mean and SD were presented for the continuous variables, while count and percentage were presented for the categorical variables. Between-group difference was tested by using Student’s *t* test or  $\chi^2$  test. To examine the association between willingness to get vaccinated and potential risk factors, willingness was dichotomized into “got/get ASAP” and “else.” A logistic regression model was used with “got/get ASAP” as the dependent variable and race/ethnicity, school plan, flu vaccine status, and comorbidities as independent variables, stratified by age groups. As actual and planned EUA status varied across the 3 age groups, we expected that risk factor effects would also vary by age, so multivariate logistic regression models were run, stratified by age group. All analyses were performed by using SAS 9.4 (SAS Institute Inc, Cary, NC).

## RESULTS

### Demographics and Willingness to Vaccinate

This diverse sample of 352 included parents of Asian (18.6%), Black/African-American (9.3%), and Hispanic/Latina(o) (16.5%) descent, 56.5% of whose index child was younger than 12 years. Autism was the predominant diagnosis (62.2%), followed by attention-deficit/hyperactive disorder (ADHD)/learning (30.1%) and developmental delay (25.3%) (Table 1). Although New York State (NYS) announced in May 2021 that its schools would open for in-person learning in Fall 2021,<sup>29</sup> 24% of parents were not planning for their child to attend school in-person in September. Most children’s routine vaccinations were up to date (94.0%), but only 70.5% of age-eligible children had received a flu shot in the last year. The top ranked vaccination settings, which varied by age, were doctor’s office, other ( $p < 0.001$ ), and home ( $p.01$ ).

Willingness to vaccinate differed by race/ethnicity ( $p < 0.01$ ). White and Asian parents were highly willing to vaccinate their child (66.5% and 64.5%, respectively), while 29.0% of Black/African-American and 20.0% of Hispanic/Latino(a) parents did not intend to. Willingness also differed by child age ( $p < 0.001$ ). High willingness was reported by parents of 73.9% of adolescents, 50.0% of school-age children, and 36.0% of young children. Autism was the only diagnosis associated with willingness to vaccinate ( $p < 0.01$ ). Parents of children with autism (vs. without autism) were more than twice as likely to “definitely not” want their child vaccinated (19.2% vs. 8.3%). Routine and flu vaccination status were both associated with willingness to vaccinate ( $p < 0.001$ ); school plans and preferred vaccination site were not.

**Table 1. Demographics and Willingness to Vaccinate**

	N (%)	Got/Get ASAP	Wait/If Required	Definitely Not	
Overall	352	202 (57%)	97 (28%)	53 (15%)	
Race/ethnicity (parent):**					
Asian	62 (18.6%)	40 (64.5%)	20 (32.3%)	2 (3.2%)	
Black/African-American	31 (9.3%)	13 (41.9%)	9 (29.0%)	9 (29.0%)	
Hispanic/Latino(a)	55 (16.5%)	23 (41.8%)	21 (38.2%)	11 (20.0%)	
White	164 (49.1%)	109 (66.5%)	38 (23.2%)	17 (10.4%)	
Other	22 (6.6%)	12 (54.5%)	6 (27.3%)	4 (18.2%)	
Language of survey:					
English	308 (87.5%)	177 (57.5%)	80 (26.0%)	51 (16.6%)	
Korean	34 (9.7%)	21 (61.8%)	11 (32.4%)	2 (5.9%)	
Other	10 (2.8%)	4 (40.0%)	6 (60.0%)	0 (0.0%)	
Preferred vaccine site (#1):					
Doctor's office	252 (71.6%)	140 (55.6%)	77 (30.6%)	35 (13.9%)	
Other***	60 (17.0%)	21 (35.0%)	17 (28.3%)	22 (36.7%)	
Home**	54 (15.3%)	24 (44.4%)	14 (25.9%)	16 (29.6%)	
Child age***					
0–5 yr	75 (21.3%)	27 (36.0%)	26 (34.7%)	22 (29.3%)	
6–11 yr	124 (35.2%)	62 (50.0%)	50 (40.3%)	12 (9.7%)	
12–17 yr	153 (43.5%)	113 (73.9%)	21 (13.7%)	19 (12.4%)	
School plans:					
Current: in-person	215 (61.1%)	128 (59.5%)	55 (25.6%)	32 (14.9%)	
Current: Other	137 (38.9%)	74 (54.0%)	42 (30.7%)	21 (15.3%)	
Fall: in-person	269 (76.4%)	154 (57.2%)	76 (28.3%)	39 (14.5%)	
Fall: Other	83 (23.6%)	48 (57.8%)	21 (25.3%)	14 (16.9%)	
Routine vaccines current:***					
Yes	331 (94.0%)	195 (58.9%)	92 (27.8%)	44 (13.3%)	
No	21 (6.0%)	7 (33.3%)	5 (23.8%)	9 (42.9%)	
Flu vaccine past 12 mo.:***					
Yes	248 (70.5%)	158 (63.7%)	67 (27.0%)	23 (9.3%)	
No	104 (29.5%)	44 (42.3%)	30 (28.8%)	30 (28.8%)	
Diagnosis: <i>not mutually exclusive</i> . <sup>a</sup>					
Autism*	Yes	219 (62.2%)	124 (56.6%)	53 (24.2%)	42 (19.2%)
	No	133 (37.8%)	78 (58.6%)	44 (33.1%)	11 (8.3%)
ADHD/learning	Yes	106 (30.1%)	65 (61.3%)	26 (24.5%)	15 (14.2%)
	No	246 (69.9%)	137 (55.7%)	71 (28.9%)	38 (15.4%)
Developmental delay	Yes	89 (25.3%)	55 (61.8%)	23 (25.8%)	11 (12.4%)
	No	263 (74.7%)	147 (55.9%)	74 (28.1%)	42 (16.0%)
Intellectual disability	Yes	61 (17.3%)	41 (67.2%)	13 (21.3%)	7 (11.5%)
	No	291 (82.7%)	161 (55.3%)	84 (28.9%)	46 (15.8%)
Blindness + hearing + others	Yes	99 (28.1%)	57 (57.6%)	24 (24.2%)	18 (18.2%)
	No	253 (71.9%)	145 (57.3%)	73 (28.9%)	35 (13.8%)

Differences in "willingness": \* $p < 0.05$ , \*\* $p < 0.01$ , \*\*\* $p < 0.001$ . <sup>a</sup>Differences in "willingness" between children with (yes) diagnosis vs. without (no).

## Concerns About Getting Vaccine

Among parents who were not highly willing to vaccinate their child ( $n = 150$ ), the most frequently reported "big reasons" for concern were side effects (88.7%), noninclusion of children with disabilities in clinical trials

(80.0%), vaccine being too new and wanting to see effect on others (75.2%), effect on child's development (68.0%), and not wanting child to be used as an experiment (66.7%) (Table 2). Concerns related to getting COVID from the vaccine (18.8%), the low rate of serious

**Table 2.** Concerns About Getting Vaccine: Total Sample and by Age

	N (%)	0-5	6-11	12-17
Overall	N = 150	N = 48	N = 62	N = 40
COVID concerns				
Side effects	133 (88.7%)	45 (33.8%)	55 (41.4%)	33 (24.8%)
COVID vaccine not safe*	72 (48.0%)	27 (37.5%)	21 (29.2%)	24 (33.3%)
Children with disabilities not in trials	120 (80.0%)	43 (35.8%)	46 (38.3%)	31 (25.8%)
Too new, want to see effect on others	112 (75.2%)	37 (33.0%)	46 (41.1%)	29 (25.9%)
COVID not serious enough in children to need vaccine	34 (22.8%)	9 (26.5%)	13 (38.2%)	12 (35.3%)
Vaccine might contain microchip, 5G, change DNA	36 (24.2%)	14 (38.9%)	10 (27.8%)	12 (33.3%)
Will not decide until trials in this age group	67 (60.9%)	31 (46.3%)	36 (53.7%)	N/A
Vaccine concerns				
Do not trust vaccines in general**	35 (23.5%)	14 (40.0%)	6 (17.1%)	15 (42.9%)
Do not trust health care system**	32 (21.6%)	11 (34.4%)	6 (18.8%)	15 (46.9%)
Specific child/family concerns				
Effects on child's development	102 (68.0%)	37 (36.3%)	40 (39.2%)	25 (24.5%)
Effects on fertility	60 (40.3%)	20 (33.3%)	26 (43.3%)	14 (23.3%)
Child might get COVID from vaccine	28 (18.8%)	9 (32.1%)	11 (39.3%)	8 (28.6%)
Do not want child used as "experiment"	100 (66.7%)	38 (38.0%)	36 (36.0%)	26 (26.0%)
Religious or cultural reasons	18 (12.1%)	6 (33.3%)	5 (27.8%)	7 (38.9%)
Needle anxiety	46 (30.9%)	17 (37.0%)	17 (37.0%)	12 (26.1%)
Vaccine site will not support child's needs	47 (31.5%)	17 (36.2%)	19 (40.4%)	11 (23.4%)
My child is too young for this vaccine	37 (77.1%)	37 (100%)	N/A	N/A
Child is getting too many vaccines now	14 (29.8%)	14 (100%)	N/A	N/A

Age differences: \* $p < 0.05$ , \*\* $p < 0.01$ .

COVID illness in children (22.8%), vaccines containing microchips/5G/changing DNA (24.2%), and needle anxiety (30.9%) were less common. Among parents of children aged 0 to 5 years, 100% indicated that their child was too young for the vaccine.

There were few significant age-related differences across the 16 listed concerns (18 concerns for 0- to 5-year-olds). These included concerns about the vaccine's safety ( $p < 0.05$ ), which was highest for children aged 0 to 5 years (37.5%) compared with 6- to 11-year-olds (29.2%) or 12- to 17-year-olds (33.3%). Lack of trust in vaccines generally ( $p < 0.01$ ) and in the health care system ( $p < 0.01$ ) was higher for the young children and adolescents, although sample sizes were small. A minority of parents ( $n = 19$ ) offered additional reasons for concerns. These included lack of FDA approval/emergency use authorization (EUA) ( $n = 1$ ), cardiac/myocarditis ( $n = 2$ ), metals in vaccine ( $n = 2$ ), and do not trust pharmaceutical companies/no liability ( $n = 2$ ).

### Predictors of "Got/Will Get ASAP" Vaccine

In adjusted models, compared with White parents, the odds of high willingness to vaccinate 0- to 5-year-old children were lower for Black (odds ratio [OR] = 0.06; 96% confidence interval [CI], 0.01-0.50) and Hispanic (OR = 0.12; 95% CI, 0.01-1.09) parents. A diagnosis of

ADHD was negatively associated with high willingness for age 5 or younger (OR = 0.02, 95% CI, <0.001-0.622) (Table 3). Among parents of 6- to 11-year-olds, *reduced* odds of being highly willing were reported by Hispanic (vs. White) parents (OR = 0.23; 95% CI, 0.06-0.90). There were no significant predictors in model for 12- to 17-year-olds related to demographic factors; however, the odds of high willingness to vaccinate were greatest among those whose children who had a flu vaccine in the past 12 months (OR = 5.84; 95% CI, 2.43-14.03).

### DISCUSSION

This article reports on novel data from more than 350 parents of children with developmental disabilities (DDs) in New York State (NYS) regarding COVID-19 vaccines. Compared with the general population, parents of children with DD seemed more willing to vaccinate their children (for context, study data were collected *after* vaccine emergency use authorization (EUA) for 12- to 15-year-olds in May 2021—which expanded the December 2020 EUA for 16-year-olds and older—and *before* the October 2021 EUA for 6- to 11-year-olds<sup>21</sup>). Parents of 73.9% of 12- to 17-year-olds got or would get as soon as possible (ASAP) the vaccine for their child with a DD versus 52% in the September 2021 Kaiser Family Foundation (KFF) Vaccine Monitor. Similarly, willingness to get

**Table 3.** Predictors of “Got/Get ASAP” Vaccine for Child

Level	0–5 Years			6–11 Years			12–17 Years		
	Odds Ratio	Lower 95% CI	Upper 95% CI	Odds Ratio	Lower 95% CI	Upper 95% CI	Odds Ratio	Lower 95% CI	Upper 95% CI
Race (vs. White)									
Asian	0.16	0.02	1.34	0.94	0.30	2.98	1.39	0.34	5.59
Black	0.06**	0.01	0.50	1.10	0.20	6.13	1.06	0.17	6.47
Hispanic	0.12*	0.02	0.72	0.23*	0.06	0.90	0.60	0.19	1.95
Others	0.09	0.01	1.09	0.79	0.16	3.84	1.98	0.33	12.07
Current schooling									
Any in-person (vs. none)	0.94	0.24	3.57	2.03	0.70	5.94	0.997	0.39	2.58
Fall school plan									
Any in-person (vs. none)	0.78	0.14	4.34	0.54	0.17	1.72	1.09	0.35	3.40
Flu vaccine, recent									
Got vaccine (vs. not)	5.13	0.72	36.48	2.24	0.88	5.75	5.84***	2.43	14.03
Diagnosis (vs. no)									
Autism	2.97	0.59	14.80	2.18	0.88	5.40	0.98	0.36	2.64
ADHD	0.02*	<0.001	0.62	1.51	0.67	3.42	0.60	0.23	1.61
Developmental delay	2.90	0.60	14.12	0.81	0.31	2.12	1.51	0.44	5.13
Intellectual disability	5.22	0.49	55.61	1.50	0.49	4.65	1.26	0.36	4.50
Vision/hearing/other	0.25	0.04	1.66	1.66	0.59	4.64	0.48	0.17	1.40

\**p* < 0.05, \*\**p* < 0.01, \*\*\**p* < 0.001. ADHD, attention deficit/hyperactive disorder; ASAP, as soon as possible; CI, confidence interval.

the vaccine ASAP was higher for school-age children in our study than in the KFF survey (50% vs. 34%) and in the youngest children (36% vs. 23%).<sup>22</sup> Furthermore, as of mid-December 2021, 19% of 5- to 11-year-olds and 62% of 12- to 17-year-olds in the United States had received at least 1 vaccine dose.<sup>30</sup> These proportions are lower than our “get/get ASAP” study data from several months earlier at these same ages.

To be sure, findings from this NYS sample may not be generalizable to the United States given pre-pandemic demographic differences and state-specific COVID-19 parameters such as infection, morbidity, and vaccination rates. For example, 49% of the United States parents in a prior survey intended to vaccinate their youngest child—mean age of 5 years<sup>19</sup>—compared with 62% of New York City parents using the same survey.<sup>20</sup> In addition, as of March 2022, more 5- to 11-year-olds in NYS had received an initial vaccine dose compared with the national average for this age group (42% vs. 33%), as had more 12- to 17-year-olds (82% vs. 67%).<sup>31</sup> Similarly, at the time of our study, NYS’s overall vaccination rates (children and adults) were approximately 8% above the national average.<sup>30</sup> Potential geographic confounding and lack of DD-specific surveillance data thus limit comparisons with the general (vs. DD-specific) population.

To meet this demand, the top ranked vaccination settings were doctor’s offices, followed by public sites and schools. This ordering parallels NYS’s roll out, which prioritized doctor’s offices and community pharmacies. Unlike health care settings that care for children with IDD, not all community sites and schools have IDD-

trained staff and behavioral supports needed to provide positive vaccine experience for children with IDD (e.g., visual schedules, social stories, and sensory distraction materials). Efforts are also needed to increase access to health care visits (e.g., flexible scheduling, transportation assistance) and to emphasize that COVID-19 vaccinations should not be delayed until their child’s next well-child visit. In addition, vaccine outreach and education must be tailored to the DD population’s concerns about side effects, noninclusion of children with disabilities in vaccine trials, and effects on their development. Notably, these DD-specific concerns overlap with those identified for adults with DD, such as representation of persons with DD in vaccine trials and not wanting to be “used as experiment.”<sup>27</sup> These findings underscore broader issues about the lack of inclusion of persons with DDs in disease surveillance and research. Finally, outreach to families of color is needed to address perceptions of a health care system that has often been difficult to access, not met their needs, and oftentimes failed to deliver respectful care.

Fewer children with autism and other DDs are current with their recommended vaccinations,<sup>13–15</sup> largely because of long debunked myths.<sup>15</sup> Not surprisingly, study participants not intending to vaccinate their child (albeit just 15% of the sample) were 3 times as likely to report their child was not up to date with routine vaccinations or the flu shot. Findings by specific diagnosis were nuanced. Unadjusted for age or other factors, higher willingness was comparable across diagnoses, although relatively more parents of children with (vs. without) autism did not intend to vaccinate their child. This

finding suggests that just a subset of parents of children with autism had strong preferences against vaccination. The *only* significant finding for diagnosis in age-stratified multivariate models was attention deficit/hyperactivity disorder (ADHD)'s association with *lower* odds of young children getting the vaccine. Thus, parents' decisions about COVID-19 vaccines for their children with DDs are multifactorial and may not mirror prior data about vaccines and diagnosis.

Regarding race/ethnicity, a higher *overall* percentage of Black and Hispanic parents were not willing to vaccinate their child. Similarly, some people of color in the United States were initially more vaccine-hesitant—although gaps with White non-Hispanics have largely narrowed.<sup>30</sup> There is valid and historical mistrust in the health care system among communities of color in this country, which likely affected initial hesitance. In response, culturally and linguistically competent outreach and education sought to target mistrust and likely reduced hesitance. In contrast to our findings presented in Table 1, in age-stratified models, there were no significant differences in “high willingness” by any race/ethnicity for adolescents and only lower odds for Hispanic (vs. White) for school-age children. By contrast, White parents of young children were significantly more likely to get the vaccine ASAP than all other race/ethnic groups. These findings suggest that parents of color are balancing health care system mistrust and concerns about the vaccine with short-term and long-term concerns about their child's health and the COVID-19 vaccine's potential for families to get back to or maintain their routines.

To the best of our knowledge, this is the first such parent/caregiver data in the DD population, thus filling a gap in knowledge for this vulnerable population. We note that national data track COVID-19 vaccination rates only for adults (i.e., 18 years and older) by functional disability (i.e., mobility, cognitive) but not for children with disability or for children or adults with developmental disabilities.<sup>30</sup> Another strength is the sample's race/ethnic and linguistic diversity, including nearly half persons of color and 12.5% who completed the survey in a language other than English. In addition, inclusion of vetted items, such as the KFF Vaccine Monitor classifications for willingness to vaccinate, enables comparisons. A limitation related to use of KFF items is that it may have been unclear to parents of children younger than 12 years that the free vaccine for their child would only be offered after appropriate safety data and an EUA were obtained. Another limitation is the convenience sample, which may bias toward families connected to the DD networks from which we recruited. In addition, as noted above, findings may not be representative of the DD community nationwide. Finally, the sample may exclude parents who were unable to access and navigate a web-linked survey.

## CONCLUSION

Children with developmental disabilities (DDs) are vulnerable to both the health risks posed by COVID-19

and the pandemic's impact on developmental services, in-person schooling, and socialization opportunities. The apparently high willingness of parents of children with DDs to vaccinate their children is encouraging, although trust will need to be engendered among parents of young children of color to actualize these intentions. Additional monitoring data are needed to track COVID-19 disease, vaccine intentions, and vaccination rates in children with DD.

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