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Quality of life, satisfaction with care, and the experiences of adults with intellectual and developmental disabilities before and during COVID-19

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ABSTRACT

Background: Adults with intellectual and developmental disabilities (IDD) experienced significant disruptions in their access to health care, support services, and essential daily activities such as work, leisure, and routine daily care during COVID-19.

Objective: The purpose of this study was to describe overall experiences related to COVID-19 among adults with IDD, including the vaccination process, quality of life (QoL), and service satisfaction before and during the pandemic.

Methods: A longitudinal statewide survey of adults with IDD receiving long-term care support using a combination of self- and care partner report was completed prior to (2017; n = 331) and during (2021; n = 206) the pandemic.

Results: Qualitative results identified specific vaccine barriers, vaccine decision influencers, and general experiences during COVID-19 for adults with IDD. The importance of support staff, vaccine availability, disruption in daily activities, social context, and mental health implications were noted in responses to all three topics. Quantitative results showed lower QoL during COVID-19 (M = 2.99 vs. 3.14, $p = .028$); however, when reporter (self vs. care partner) and age were added to the model, differences between pre-vs. during-COVID were no longer significant. No significant differences in satisfaction of services were noted pre-vs. during-COVID-19. Ninety-six percent of respondents reported access to the vaccine, and 16 % experienced barriers getting the vaccine. QoL was associated with receiving the COVID-19 vaccine ($r = 0.15$, $p = .036$), level of agreement that the vaccine is safe ($r = 0.17$, $p = .024$), and level of agreement that getting the vaccine will help protect other vulnerable people in the community ($r = .25$, $p = .001$). Level of satisfaction with quality of services was also associated with level of agreement that the vaccine is safe ($r = 0.15$, $p = .048$).

Conclusions: Overall, a better understanding of service continuation, support practices, and experiences related to COVID-19 will prepare us for future environmental and health crises by identifying areas for improvement, intervention, and policy change to meet the ongoing needs of adults with IDD.

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Ethical approval

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1. Introduction

Intellectual and developmental disabilities (IDD) include a variety of neurodevelopmental disorders, commonly associated with cognitive limitations and a range of impaired adaptive functioning skills.¹ These challenges can have varying degrees of impact on everyday activities such as school, work or leisure, and basic self-care skills; thus, many adults with IDD receive supportive care services in order to support their full engagement in the community. In addition to functional limitations, people with disabilities have higher rates of co-occurring mental health issues such as anxiety and depression and chronic health conditions such as high cholesterol, obesity, hypertension, cardiovascular disease, and Type II diabetes,^{2,3} as well as lower quality of life than their peers.⁴ Importantly, adults with IDD face specific barriers to appropriate healthcare and support services including decreased knowledge of services, limited access to preventative care, financial barriers, and physical environments that are not accessible.⁵⁻⁷

Adults with IDD may experience disparities in access to, and the quality of, health care for a multitude of reasons. Previous research has documented healthcare disparities experienced by individuals with disabilities can result from difficulty creating an accessible environment, explaining procedures in understandable and digestible terminology, and ensuring the individual is fully prepared and understands next steps.^{8,9} Other barriers to health care include providers lacking population-specific medical training^{10,11}; complexity in navigating the healthcare system, including finding eligible providers and unaffordability of services^{6,10}; challenges with accessibility of the built environment, including finding transportation¹⁰; and decreased health literacy.^{6,12,13} Adults with IDD and their care partners similarly report difficulty in accessing adequate support services. For example, many parents of adults with IDD report an inadequate number of qualified support providers, frequent staff turnover that can be stressful to the adult with IDD and their family, and difficulty finding providers that are covered by their insurance and/or able to travel to their home.^{10,14,15}

While COVID-19 has had profound impacts on daily life and healthcare delivery for all individuals, it has disproportionately impacted adults with IDD.¹⁶⁻¹⁸ Other than age, having an IDD was the strongest independent risk factor for presenting with a Covid-19 diagnosis and for Covid-19 mortality.¹⁶ Differing expectations between residents and staff, difficulties wearing masks, high levels of exposure due to the nature of in-home healthcare, residential housing, and shared transportation within these populations all increased COVID-19 health risks to adults with IDD.¹⁶ Although these risks have been well documented, less work has been done to understand the measures that have been taken during this difficult time to protect this population amid the pandemic, and how these shifts have impacted the care and services received, as well as importantly, the quality of life, of individuals with IDD during this time.

While immediate COVID-19 research focused on the concerns for physical health and safety of this population, emerging studies are also examining the lived experiences of adults with IDD and the impact the pandemic has had on their quality of life. For example, Friedman (2021) found significant differences for adults with IDD in their quality of life related to continuity and security, social interactions, community activities, intimate relationships, and self-determination pre- (2019) and immediately post-COVID (2020).¹⁵ Adults with IDD have faced a unique set of challenges throughout the pandemic and as service delivery

continues to grow and change. It is important to prioritize understanding of quality of life and responsiveness of care and support services and professionals available to adults with IDD throughout the changing landscape of COVID-19.

To better understand the lived experiences of adults with IDD during the pandemic, it is also important to consider the source from which this information is gathered. While care partners can be valuable in collecting information, prioritizing communicating directly with adults with IDD themselves is critical in better understanding their lived experiences.¹⁹ Assessing internal thoughts and feelings of adults with IDD through self-reports is essential to work aimed at identifying specific barriers to care, quality of life, and in finding inclusive ways to incorporate this perspective to identify actionable points of intervention.

The present study aimed to: 1) describe adults with IDD's vaccination process and overall experiences during COVID-19, 2) compare quality of life and satisfaction with the amount and quality of healthcare and daily support services among adults with IDD pre- (2017) and during-pandemic (2021), and 3) investigate associations between QoL and satisfaction with amount and quality of services with receiving the COVID-19 vaccine, experiencing barriers to getting the vaccine, and types of concern/viewpoints about the vaccine. Aim 1 used qualitative data gathered during the 2021 (during the pandemic) data collection wave. No a priori hypotheses were identified about the adults with IDD's vaccination process and overall experiences during COVID-19. Aim 2 was investigated using two waves of a state-wide survey in which study year (2017 vs. 2021) was assessed as a predictor of the outcomes of interest. We hypothesized that quality of life and satisfaction with the amount and quality of healthcare and daily support services would be higher among adults with IDD in 2017 (pre-pandemic) than in 2021 (during-pandemic). Aim 3 used quantitative data gathered during the 2021 (during-pandemic) data collection wave. We hypothesized that individuals who reported higher quality of life and greater satisfaction with the amount and quality of healthcare and daily support services would be more likely to receive the COVID-19 vaccine, less likely to experience barriers to getting the vaccine, and have more confidence and positive viewpoints about the vaccine.

2. Methods

The current study focused on the first two waves of data collection in the statewide Long-Term Care Survey, an ongoing survey study aimed at understanding services, choices, independence, and quality of life of adults with IDD who receive state-funded long-term care disability support in the state of Wisconsin. The Long-Term Care Survey was designed in collaboration with state non-profit organizations and a Constituent Advisory Committee of people with disabilities and advocates. The current study used independent data from 2017 to 2021 (waves 1 and 2). In 2021, 15 additional questions related to COVID-19 were added.

In 2017, invitations including study information were sent to all people receiving long-term care disability support through the Wisconsin Department of Health Services. In 2021, recruitment consisted of recontacting those who provided re-contact information (n = 156/331) and additional recruitment through two community partner's listservs and research registries. Respondents were not financially compensated for completing the survey at either time point. Eligibility criteria at each wave of data collection (2017 and 2021) included: 1) 18 years of age or older, 2) living in Wisconsin, and 3) receiving long-term care disability support. The survey was available to be completed by the person receiving long-term care disability support or by someone else who could report on their behalf (e.g., care partner, supporter, guardian, family member, friend). All data was collected through online surveys using Qualtrics. Participants were directed within Qualtrics to questions worded (*you or person receiving long-term care support*) to reflect if they were reporting on behalf of someone else or for themselves. A waiver of informed consent was approved prior to recruitment and consent by

participation was used as approved by the University of Wisconsin-Madison Institutional Review Board.

2.1. Current sample

Table 1 displays sample demographic information. It is important to note that participants were not linked across time points due to the anonymous nature of the data collection. There were significantly more adults with IDD who self-reported on the survey in 2017 than in 2021 (17 % vs. 13 %; $F = 15.84, p = .00$). There were also significant differences in gender, such that there were more females in 2017 (46 %) than in 2021 (42 %). No additional demographic differences between the two samples were identified (i.e., age, race, ethnicity, disability support program type).

2.2. Measures

The current study used a subset of individual questions from a larger state-wide survey, the Long-Term Care Survey. The Long-Term Care survey is a 78-item questionnaire designed for a larger project examining the health, well-being, and community participation and choice of adults with disabilities using long-term care support in Wisconsin. The survey consists of a mix of Likert scale, yes/no, and open-ended questions with all questions being optional to answer. In the 2021 survey, additional questions about vaccinations and COVID-19 experiences were added to the survey. The current study focused on quality of life, long-term care support service satisfaction, vaccinations, and COVID-19 experiences.

2.3. COVID-19 items

Questions related to Aim 1 drew from nine Likert scale, yes/no, or multiple-choice items, and three open-ended (i.e., write-in) items from

Table 1
Participant characteristics.

	2017 (N = 331) 298 reported demographics	2021 (N = 206) 170 reported demographics	2017/2021 Comparison
Sex			
% Male	53.6	58.3	$F = 8.09, p = .01$
Chronological Age (SD)			
	36 (1.510)	36 (1.513)	$F = 0.73, p = .39$
Race/Ethnicity (allowed to select more than one) (%)			
			$F = 0.32, p = .57$
African-American	1.4	2.4	
American Indian/Alaskan Native	0.7	1.8	
Asian	0.4	0.6	
Native Hawaiian/Pacific Islander	0.0	0.6	
Bi-racial or other	1.4	0.6	
White	80.1	3.8	
Hispanic	2.9	4.7	
Reporter Status (%)			
			$F = 19.27, p = .00$
Self-report	17	13	
Secondary reporter	83	87	
Long-Term Care Disability Support Program Type			
			$F = 1.80, p = .18$
Managed Care Program			
Self-directed Program			

the 2021 survey. Table 2 displays all 12 COVID-related items from the 2021 Long-Term Care Survey. Questions on COVID-19 and vaccine attitudes and hesitancy were taken from prior work in the state of Wisconsin.²⁰

2.4. Quality of life and satisfaction with services

Questions related to Aim 2 included three items Likert scale questions. A single-item was used to assess QoL in this study, which has been determined to be valid in assessing QoL and may be beneficial as an alternative to longer instruments.^{15,19,21-24} Level of satisfaction with the amount and quality of services were also each answered by a single-item. Quality of Life was rated as Poor (1), Fair (2), Good (3), Excellent (4);

Table 2
2021 COVID questions (n = 202).

	n	%
Have you had COVID-19? (n = 202)		
Yes	26	13
No	176	87
Have you had the first or second dose of a vaccine for COVID-19? (n = 192)		
Yes	169	88
No	23	12
Has the vaccine been made available to you? (n = 193)		
Yes	185	96
No	4	2
Don't know	4	2
Have you experienced any barriers to getting the COVID-19 vaccine? (n = 193)		
Yes	31	16
No	162	84
[Open-ended, if "yes" to above] Please explain:		
When a COVID-19 vaccine became available to me, I (n = 180)		
Got it as soon as possible	151	84
Waited and saw how it worked on other people	14	8
Refused to get it	9	5
Was unsure about what to do	4	2
Please tell us how strongly you agree or disagree with the following statements about the current COVID-19 vaccines:		
Overall, the vaccine is safe for me. (n = 181)		
Definitely agree	111	61
Somewhat agree	27	15
Neither agree nor disagree	27	15
Somewhat disagree	2	1
Definitely disagree	14	8
The vaccine is forced upon me. (n = 179)		
Definitely agree	5	3
Somewhat agree	13	7
Neither agree nor disagree	39	22
Somewhat disagree	16	9
Definitely disagree	106	59
If I get the vaccine, I will help protect other vulnerable people in my community. (n = 176)		
Definitely agree	104	59
Somewhat agree	26	15
Neither agree nor disagree	34	19
Somewhat disagree	3	2
Definitely disagree	9	5
Where do you get their news and information about COVID-19?		
Parent or guardian	79	48
Television/news	70	43
Friends/living community	46	29
Primary care physician	28	17
Internet	26	16
Government resources	20	12
Not cognitively able to make their own decisions	12	7
[Open-ended] Is there anything else you'd like us to know about your vaccination decision?		
	-	-
[Open-ended] Is there anything else you'd like us to know about your vaccination decision?		
	-	-

Questions were slightly changed in wording based on the person answering the survey. For example, "I" was replaced with "they" when answered by person reporting behalf on someone receiving long-term care support.

*This question was worded in the context of availability of vaccinations and boosters at time of survey.

Service satisfaction questions was rated as Very dissatisfied (1), Dissatisfied (2), Neither satisfied or dissatisfied (3), Satisfied (4), Very satisfied (5). All questions included for the current study can be found in [Appendix A](#).

2.5. Data analysis

Because of the anonymous nature of the survey, the data were assumed to be independent samples. The 2017 and 2021 data were merged and study year was added as a dichotomous grouping variable. Data for each of the variables of interest were included, even if the participant had other missing data (e.g., chose not to provide demographic information).

2.6. Aim 1: COVID-19 experiences

To address Aim 1, the twelve descriptive COVID-19 questions added for the 2021 data collection were exported to and analyzed in SPSS. Counts and percentages were reported for all yes/no, Likert, and multiple-choice questions. One question asked where the adult with IDD gets their news and information about COVID-19, this question allowed a short write-in answer. This item was double coded by an undergraduate research assistant and by the first author. Disagreements were discussed with a third reviewer and a senior author on the manuscript, until consensus was reached. Categories were not exclusive; thus, one participant could have received multiple category codes for where they got their news about COVID-19 (e.g., “The web, TV, newspapers, and people that I work with”).

Qualitative content analysis was used for three open-ended response questions related to COVID-19. Qualitative responses were exported from Qualtrics and de-identified. A total of 114 of the 206 (55 %) participants answered at least one of the open-ended questions. First data was analyzed in response to each individual question. Second themes across all three questions were reviewed to identify similar responses,

The qualitative content analysis was completed by four research team members (two primary investigators and two graduate students) using the process described by Vaismoradi et al. (2016). Themes were identified using the four step process of development; 1) initialization, 2) construction, 3) rectification, and 4) finalization.²⁵ Initially, all team members independently reviewed and coded the data, looking for overlaps and patterns within and across responses while keeping reflective notes on their process and observations. Next, the team met to start the construction phase of analysis by organizing their independent codes and comparing across team members. Codes that were similar between research team members clustered together and assigned initial theme descriptions. An iterative process of comparing codes and notes and returning to the data to develop consensus on category labels and definitions was implemented. In the rectification phase, research team members returned to their dataset to verify that the developed categories and definitions represented the dataset in entirety and were distinct from one another. Related literature was reviewed to relate themes to current knowledge.

In the finalization phase, all research team members reviewed the proposed final themes and definitions. In addition, the qualitative and quantitative results were reviewed together to integrate the findings together and draw conclusions.

2.7. Aim 2: quality of life and satisfaction with services

Aim 2 was investigated by fitting four linear regression models, one for each quantitative outcome variable of interest (quality of life, satisfaction with *amount* of services, and satisfaction with *quality* of services) in a stepwise manner. In the first iteration, base models were fit with study year (2017 vs. 2021) as the predictor. In the second series of models, covariates based on demographic differences between 2017 and 2021 (sex of the individual receiving long-term care support and

reporter [individual receiving support vs. someone on their behalf]) were added. In the final models, age was also added as a covariate as research has documented associations between age and both quality of life and service satisfaction.^{26–28}

2.8. Aim 3: associations between QoL, service satisfaction, and COVID-19 vaccination attitudes

First we explored the association between each of the three main variables of interest: QoL, satisfaction with *amount* of services, and satisfaction with *quality* of services and five COVID-19 vaccine attitude variables: 1) receipt of the COVID-19 vaccine (yes/no), 2) experiencing barriers to getting the vaccine (yes/no), 3) level of agreement with the statement: “Overall, the vaccine is safe for me,” 4) level of agreement with the statement: “The vaccine is forced upon me,” and 5) level of agreement with the statement: “If I get the vaccine, I will help protect other vulnerable people in my community.” These associations were first tested through bivariate correlations. If a significant correlation was present, follow-up ANOVAs were performed for dichotomous variables (1 and 2), or linear regression analyses were performed for ordinal variable (3, 4, 5).

3. Results

Results are presented using self-reporter language (i.e., participants refer both to those self-reporting and those for whom care partners are reporting on their behalf). In the 2017 sample, participants were 54 % male and had an average age of 36. In 2021, 58 % were male and the average age was 29. There were no statistically significant differences between the 2017 and 2021 samples in age category, ethnicity, or long-term care disability support program type (i.e., managed care program vs. self-directed program). There were more females in the 2017 cohort (46 %) than in 2021 (42 %), and more self-reporting people in 2017 (17 %) than in 2021 (13 %). See [Table 1](#).

3.1. COVID-19 descriptive results

In 2021, 13 % (n = 25) of people with a disability reported that they had COVID-19 at least once. While 96 % (n = 185) of the sample reported that a vaccine had been made available to them, 16 % (n = 31) reported experiencing barriers to getting the COVID-19 vaccine. Eighty-four percent (n = 152) of participants reported that they got the vaccine as soon as possible. When asked where they get their news and information about COVID-19, 48 % (n = 79 of the 146 participants that answered this question) reported that they got their information from a parent or guardian, 43 % (n = 70) from television/news, 29 % (n = 46) from friends/living community, 17 % (n = 28) from their primary care physician, 16 % (n = 26) from the internet, and 12 % (n = 20) from government resources. Interestingly, 7 % (n = 12) of respondents wrote-in that the individual was not cognitively able to make their own decisions. See complete results in [Table 2](#).

3.2. COVID-19 qualitative results

In Aim 1, we described overall experiences during COVID-19 and the vaccination process of adults with IDD. A qualitative content analysis was used to identify potential barriers to receiving the vaccination, what influenced vaccination decisions, and additional information about COVID-19 experiences. Three distinct Barriers were identified (1) External Barriers, (2) Individual Differences, and (3) Knowledge Dissemination and Accessibility. These barriers needed to be negotiated even if they may not have necessarily prevented long-term care recipients from receiving vaccinations or boosters. Seven themes were identified as influencing decisions about receiving a vaccination or booster: (1) Difficult Choice, (2) Not Their Decision, (3) Personal Protective Equipment, (4) Social Motivation and Self-Determination, (5)

Support Staff, (6) Uncertainty, and (7) Vaccine Access and Accessibility. Seven additional themes were identified from adults with self-reporting and care partners as important to their COVID-19 experiences: (1) Information and Vaccine Availability, (2) Knowledge Translation, (3) Disrupted Daily Routines, (4) Isolation and Increased Mental Health Needs, (5) Politicized Nature of COVID-19, (6) Social Motivation, and (7) Support Staff. Although the identified themes were in response to unique questions, similar topics were observed across themes. The positive or negative role of support staff of providing quality care, access to resources, or facilitating/preventing vacation access during the pandemic was prevalent in responses to all three questions. COVID-19 information and vaccination accessibility was also an important factor across all three questions. Disruption in daily activities, social motivation/context, and mental health implications were salient themes that influenced vaccination decision making and described general COVID-19 experiences. See Table 4 for definitions and examples to illustrate each theme.

3.3. Quality of life from pre-to During-COVID

In Aim 2, we compared quality of life and satisfaction with the amount and quality of healthcare and daily support services among adults with IDD pre- (2017) and during-pandemic (2021). Regression model assumptions were tested using correlation matrices, histograms, and residual plots. No multicollinearity was evidenced with the highest correlation between QoL and any of the predictors was .14. While the QoL variable was slightly skewed to the left (i.e., the bulk of the sample reported ‘good’ or ‘excellent’ QoL), residual plots were normally distributed. Model fit and variance proportions are reported in Table 3. With each stepwise model, the residual sum of squares decreased, indicating better model fit. Although the change in R² was very small across models, it did increase, indicating that more variance in QoL was explained by the independent variables in each subsequent model.

At both time points, most respondents reported good or excellent quality of life (85 % in 2017 and 78 % in 2021). In the base model, there was a significant difference in QoL between 2017 and 2021, with QoL being higher in the 2017 cohort than in the 2021 cohort (M = 3.14, SD = 0.76 vs. 2.99, SD = 0.77; F = 4.84, p = .028). In Model 2 with reporter and sex added as covariates, QoL was predicted by reporter across time

points, with higher QoL reported by a care partner than by adults with IDD (M = 3.12 vs. 2.90, p = .032). In this model, study year no longer predicted QoL. In the final model, age was also added and predicted QoL such that younger people had higher reported QoL than older people across time points (p = .009).

3.4. Satisfaction with the amount and quality of services

In Aim 3, we investigated associations between QoL and satisfaction with amount and quality of services with receiving the COVID-19 vaccine, experiencing barriers to getting the vaccine, and types of concern/viewpoints about the vaccine. Regression model assumptions were tested as above. No multicollinearity was evidenced with the highest correlation between satisfaction with amount of services and any of the predictors was .03, and between satisfaction with quality of services and any of the predictors was .04. Both satisfaction with amount and quality of services variables were slightly skewed to the left (i.e., the bulk of the sample reported ‘satisfied’ or ‘very satisfied’); yet, residual plots were normally distributed. Similar to above, with each stepwise model for both satisfaction with amount and quality of services, the residual sum of squares decreased, indicating better model fit. Although the change in R² was very small across models, it did increase, indicating that more variance in satisfaction was explained by the independent variables in each subsequent model.

At both time points, most respondents reported being satisfied or very satisfied with the amount (75 % in 2017 and 79 % in 2021) and quality (81 % in 2017 and 82 % in 2021) of their long-term care services. As shown in Tables 4 and in the base models for each outcome (satisfaction with amount and satisfaction with quality of care), study wave (2017/2021) was not a significant predictor of satisfaction with amount or quality of care between 2017 and 2021. Similarly, there were no significant predictors (study year, sex, reporter, age) of satisfaction with amount or satisfaction with quality of services in models in which covariates were added (see Models 2 and 3 in Table 4).

3.5. Associations between QoL, service satisfaction, and COVID-19 vaccination status, barriers, and types of concern

Associations between QoL, service satisfaction, and COVID-19

Table 3 Piecewise regression model regression coefficients.

Quality of Life									
	Model 1			Model 2			Model 3		
Predictors	B	se	p	B	se	p	B	se	p
Study Year	-0.04	0.02	.028	-0.02	0.02	.252	-0.02	0.02	.364
Reporter	-	-	-	0.21	0.10	.032	0.17	0.10	.080
Sex	-	-	-	-0.04	0.07	.593	-0.03	0.07	.716
Age	-	-	-	-	-	-	-0.06	0.02	.009
R ²	.009			.013			.028		
Residual Sum of Squares	316.12			251.52			243.79		
Satisfaction with Amount of Care									
	Model 1			Model 2			Model 3		
Predictors	B	se	p	B	se	p	B	se	p
Study Year	-0.02	0.03	.471	-0.02	0.03	.533	-0.02	0.03	.480
Reporter	-	-	-	0.11	0.14	.440	0.12	0.14	.412
Sex	-	-	-	-0.02	0.10	.845	0.01	0.10	.963
Age	-	-	-	-	-	-	-0.00	0.03	.904
R ²	.001			.002			.003		
Residual Sum of Squares	549.21			521.51			510.98		
Satisfaction with Quality of Care									
	Model 1			Model 2			Model 3		
Predictors	B	se	p	B	se	p	B	se	p
Study Year	-0.02	0.03	.390	-0.02	0.03	.444	-0.02	0.03	.441
Reporter	-	-	-	0.11	0.14	.427	0.10	0.14	.478
Sex	-	-	-	0.00	0.10	.966	0.01	0.10	.889
Age	-	-	-	-	-	-	-0.01	0.04	.775
R ²	.002			.002			.003		
Residual Sum of Squares	540.93			519.34			517.32		

Table 4
Vaccination barriers, decisions, and COVID – 19 experiences.

Vaccination Barriers
<p>Theme, Definition, and Examples</p> <p>1. External Barriers: Barriers related to external physical factors such as transportation, overall accessibility, support staff, and availability of vaccination in their area. “Staff resist getting him his vaccine due to what appear to be strong political opposition to vaccination. I have been asking guardian to get staff to vaccinate him since March of this year.”; “Can’t get out (to get vaccinated), no way to get there or money to do so”</p> <p>2. Individual Differences: Barriers related to individual factors such as sensory profile, behavioral challenges, or anxiety. “The person does not like crowds or new places.”; “He is afraid of Hospitals and clinics”; “He is unable to mask. He is difficult to control.” <i>I was very fortunate that we could get his vaccine done with him in the car.”</i></p> <p>3. Knowledge Dissemination and Accessibility: Barriers due to decreased access to reliability knowledge that was accessible for community vaccine providers, care partners, person with a disability, and support staff. “Once qualified took a lot of research to find an actual location that would administer vaccine. Receiving long term care through Medicaid services was not recognized by many vaccine providers as a qualification for the vaccine in early spring 2021. It was not listed as a “box to check off” for eligibility.”</p>
Vaccination Decisions
<p>Theme, Definition, and Examples</p> <p>1. Difficult Choice: Described concern and frustration with vaccination process, related restrictions, and weighing the benefits or individual cost of getting the vaccination, particularly negative side effects. “Medically compromised with health concerns made it difficult to determine whether risks would outweigh benefits”; “She has many hard side effects from most medications, so it was decided that she should not get the vaccine.”</p> <p>2. Not Their Decision: Care partners reported that it wasn’t the LTC recipient’s decision as to whether they received the vaccination. “This is a choice made for her by her mother”; “Due to cognitive impairment all decisions are made by us parents who are also legal guardians. Our son needs 24/7 care in all aspects of his life. We try and make the decisions he would want.”</p> <p>3. Personal Protective Equipment (PPE): Described successes and challenges with LTC recipients using PPE as a reason to receive the vaccination. “His mother and I, as parents and legal guardians, made the decision to have him get the vaccination so he would not have to wear a mask at work. It seemed that he was coming home coughing much more after having to wear the mask for several hours a day.”; “She refuses to wear a mask so the vaccination was the only way we could protect her from the virus and still go for rides and walks.”</p> <p>4. Social Motivation and Self Determination: Described being socially motivated to the get vaccine to engage in work, social activities, and daily routines. Provided an opportunity for some LTC recipients to be self-advocates in the vaccination process. “Received the vaccine because it made the person feel more comfortable going out in public and being around other people.”; “As parents and caregivers, we encouraged him to get the vaccine. He understood that it was essential to being able to see his friends and family again, and return to in-person (rather than virtual) activities.”; “She was very aware of the Covid issue. She researched where she could get the vaccine in her area and scheduled the appointment.”</p> <p>5. Support Staff: Decisions related to receiving the vaccination or related information was influenced or dictated by support staff or living context. “His APH arranged for residents to get both doses within their home.”; “The Group Home was not pro-active on getting all residents & staff vaccinated when they were able.”; “I can’t believe he still doesn’t have the vaccine. He has at times told them he wants it, but often he accedes to their political outlook. And now, he has staff who’ve tested positive for COVID. I’m terrified my son will get sick.”</p> <p>6. Uncertainty: A general feeling of uncertainty was described by many that included anxiety and concern about implications of extended isolation, disrupted daily routines, risks factors of contracting or being exposed to COVID 19. “She has been experiencing a great amount of anxiety due to the Covid-19. Worries about exposure, stresses over going out in public, fears she has symptoms or others in the family do, fear of the unknown as it is all very confusing to her most days.”</p> <p>7. Vaccine Access and Availability: Described frustration with lack of control over vaccination access and availability. Expressed the need to have access earlier and increased accessibility with more options related to location, supports available at the locations, appointment availability and types of vaccines available. “Should have been allowed to get the vaccine earlier”; “More accessible option (locations, supports, appointments, types of vaccines); “Individual was eager to get the vaccine as soon as eligible—but it was very difficult to identify a provider and get an appointment.”</p>
COVID-19 Experiences
<p>Theme, Definition, and Examples</p>

Table 4 (continued)

Vaccination Barriers
<p>1. COVID – 19 Information and Vaccine Availability: Difficult to access reliable information about COVID-19, especially as the restrictions and recommendations were rapidly changing. In addition, accessing the vaccination and the booster was difficult at times. “Would have been helpful for dr to talk about it more and explain it”; “The process was long and difficult to obtain the vaccine at home”; “Not all their care givers have had the vaccine for COVID. One does not believe in the vaccine and have refused the clients mother’s request to get the vaccine. They are afraid of the vaccine and think it will hurt their pregnant wife and baby on the way. We need help in getting education to these agencies (to educate their workers) who support 24 h care.”</p> <p>2. COVID – 19 Knowledge Translation: Care partners described difficulty explaining what COVID-19 was to individuals receiving LTC and they had limited understanding, which further complicated their compliance with wearing masks and social distancing. “Most days it is very confusing to her and just as difficult for me to explain it to her. Right now the biggest struggle is understanding the Delta variant and recent changes to the mask mandate. She thought it was over and now it feels as if it is starting all over again.”; “It was really difficult for him to handle the restrictions on visitors. He has since moved to assisted living and it has helped, He really thought that people forgot about him and no longer cared about him.”</p> <p>3. Disrupted Daily Routines: No longer able to go to work, limited participation in social activities, and numerous daily routines disrupted. “My son was working more for his company before COVID. His company did not let him work remotely because they deemed him to need more support. He is still only working two days a week in person. Due to covid protocols, he is not integrated very well at the company and really could have been working remotely all this time”; “The person shows extreme reluctance to participate in community events, although still goes to museums, outdoor activities, and some shopping, but avoids restaurants, libraries, or visiting friends.”</p> <p>4. Isolation and Increased Mental Health Needs: Increased anxiety and other mental health concerns due to prolonged isolation, changes in routine, or fears related to COVID-19. “The community shutdown and restrictions has had a huge negative impact on the clients mental & physical health. the client is anxiously awaiting life to ‘return to normal’ but understands it will take time and is grateful to be back at work and participating in some social activities.”; “Because of Covid and worker shortage unable to work. Self-esteem significantly impacted. Depressed.”; “The prolonged isolation and lack of stimulation has had a negative affect on her physically, mentally, socially and emotionally. We are now dealing with mental health issues.”</p> <p>5. Politicized Nature of COVID-19: Described lack of control regarding imposed restrictions and frustration about the information received about COVID-19, vaccination, and related side effects. “Feels like we are playing Russian Roulette. What’s the lesser of 2 evils. Shut off the news, We are ok. No trust in media anymore increases stress.”; “He has been upset over changes to his routine and life imposed on him by the County and certain businesses.”; His guardian was very upset that health authorities and care providers marginalized the potential adverse consequences from the “vaccine” and endorsed its safety and efficacy without any appropriate data to support their endorsement.”</p> <p>6. Social Motivation: Described altruistic reasons for getting vaccinated as wanted to protect older adults, family, friends, and others with increased risks. “She wears her mask at work and when going out to protect herself and others. She wishes others would do the same. She wanted the vaccine to protect herself and other vulnerable people friends, coworkers, and any unexpected contacts. She is very worried about immunocompromised friends”.</p> <p>7. Support Staff: Played an essential role during the pandemic providing a safe and engaging environment or a barrier to vaccinations and perceived safety. Support staff were creative in adjusting to providing care during the pandemic. However, support staff also created barriers to individuals receiving LTC receiving the vaccine or refused to get the vaccination themselves or follow similar safety protocols putting others at risk. “Throughout the pandemic, I was pleased overall with the response of his group home management and staff and how they kept my son and his three housemates safe. There were periods of time we were unable to visit, and other periods where we were allowed outside visits. My son has anxiety in general, but he seemed to handle everything well. We communicated regularly with staff and Facetimed with him when we weren’t allowed to visit in person. As a parent/guardian, I have been anxious about the refusal of some of his caregivers to get vaccinated (in conversations with them, it is very much that they are victims of disinformation regarding the vaccine) and the possibility that they could bring Covid into the house.”; “His staff have tested positive for COVID while failing to get him vaccinated despite several</p>

(continued on next page)

Table 4 (continued)

Vaccination Barriers
<i>requests by me and guardian, and some requests by my son. If he gets sick, they should be held liable for their failure to protect him. The staff are GREAT in terms of supporting him emotionally and addressing his behavioral challenges, the best he's ever had. They only fail him in regards to COVID, in my opinion."</i>

Note. LTC = long-term care. Themes are presented in alphabetical order under each heading.

vaccination status, barriers, and vaccine attitudes are presented in Table 5. QoL was associated with receiving the COVID-19 vaccine ($r = 0.15, p = .036$), such that individuals with higher QoL were more likely to have reported receiving the vaccine. A follow-up ANOVA analysis revealed a significant mean difference ($F = 4.47, p = .036$) in QoL between those who had received the COVID-19 vaccine ($M = 2.70, SD = 0.82$) compared to those who did not ($M = 3.05, SD = 0.74$). QoL was also associated with level of agreement with the statement: "Overall, the vaccine is safe for me" ($r = 0.17, p = .024$), such that individuals who agreed that the vaccine was safe reported a higher QoL. This finding was confirmed by a linear regression model ($B = 0.10, p = .024$). Level of agreement with the statement: "If I get the vaccine, I will help protect other vulnerable people in my community" was also positively associated with QoL ($r = .25, p = .001$), and confirmed by a linear regression model ($B = 0.17, p = .001$). QoL was not associated with experiencing barriers to getting the vaccine, or agreement with the statement "The vaccine is forced upon me."

Level of satisfaction with amount of services was not associated with receiving the COVID-19 vaccine, experiencing barriers to getting the vaccine, or any level of agreement with the three statements on vaccine attitudes.

Level of satisfaction with quality of services was associated with level of agreement with the statement: "Overall, the vaccine is safe for me" ($r = 0.15, p = .048$), such that individuals who reported higher satisfaction in the quality of their services were more likely to agree with the statement on safety. This finding was confirmed by a linear regression model ($B = 0.15, p = .048$). Level of satisfaction with quality of services was not associated with receiving the COVID-19 vaccine, experiencing barriers to getting the vaccine, or level of agreement with the statements on the vaccine being forced or helping to protect other vulnerable

Table 5

Associations between QoL, service satisfaction, and COVID-19 vaccination status, barriers, and types of concern.

		QoL	Satisfaction with amount of care	Satisfaction with quality of care
Receiving a COVID-19 vaccine	r	.15 ^a	.01	.08
	p	.036	.897	.282
Experiencing barriers to getting the vaccine	r	-.05	-.03	-.13
	p	.497	.726	.080
Level of agreement with the statements:				
"Overall, the vaccine is safe for me"	r	.17 ^a	.13	.15 ^a
	p	.024	.092	.048
"The vaccine is forced upon me"	r	-.11	-.08	-.14
	p	.156	.306	.067
"If I get the vaccine, I will help protect other vulnerable people in my community"	r	.25 ^b	.73	.08
	p	.001	.161	.161

Note. Receiving a COVID-19 vaccine was coded as 0 = no, 1 = yes; Experiencing barriers to getting the vaccine was coded as 0 = no, 1 = yes; Level of agreement with the statements: "Overall, the vaccine is safe for me," "The vaccine is forced upon me," and "If I get the vaccine, I will help protect other vulnerable people in my community" was coded 1 = definitely disagree, 2 = somewhat disagree, 3 = neither agree nor disagree, 4 = somewhat agree, 5 = definitely agree.

^a Correlation is significant at the 0.05 level (2-tailed).

^b Correlation is significant at the 0.01 level (2-tailed).

people in the community.

4. Discussion

COVID-19 is likely to continue to impact the entire population for years to come, similar to other ongoing societal shifts (e.g., the Great Recession).²⁹ The current study examined healthcare and vaccination access and overall experiences during COVID-19, as well as the quality of life and service satisfaction of adults with IDD before and during the COVID-19 pandemic. This study importantly identified specific barriers to the COVID-19 vaccine experienced by adults with IDD and important factors that were part of their vaccination decision-making. Further, the current study included self-reported experiences, a crucial step in understanding true barriers to care during COVID-19 that will be essential to identifying points of intervention and support. It is important to note again that significantly more participants self-reported in 2017 (17 %) than in 2021 (13 %) and results should be interpreted accordingly. Future directions for this work will continue to document the impact of COVID-19 on the health and well-being of adults with IDD as its long-term impacts continue to unfold. We will build on this work by simultaneously evaluating current community responses to mitigate those effects and address barriers to continued access to services, vaccines and boosters, and other supports during COVID-19.

Qualitative results of this study added valuable context to the complexity of care satisfaction and expectations during COVID-19. Having access to reliable information about COVID-19, vaccinations, and ongoing rules and restrictions was conveyed to be important for adults with IDD and their care partners, particularly regarding how to obtain vaccinations. Adults with IDD are often in a higher risk category related to COVID-19 and experienced substantially greater negative impacts up to this point during the pandemic.¹⁶ Providing reliable information in an accessible format in the current ongoing COVID-19 pandemic or in future health crises that is targeted toward adults with IDD, their care partners, and support staff is an essential tool that could facilitate knowledge translation and inform health care decisions.

Of the $n = 192$ respondents, approximately 88 % reported that they had gotten a COVID-19 vaccine and 84 % said that they got it as soon as they were able. This is in line with previous research that ~84 % of individuals with IDD intended to or had received the vaccine.³⁰ Interestingly, however, previous studies have also revealed significantly lower reports of vaccine receipt of family members of those with IDD (~74 %), as well as significant differences between preferences for oneself to get the vaccine (75 %) versus for others for whom the respondent makes health decisions (68 %).³⁰

In our study, many individuals (48 %) received their information about COVID-19 vaccines from a parent/guardian, highlighting their role in those choices. While some adults with IDD advocated for their preferred choice regarding vaccination, other individuals' supporter made the decision regarding vaccination for them. As mentioned above, a prominent theme was that it was "Not Their Decision" as to whether the adult with IDD received the vaccination. Support staff were gate keepers for facilitating or preventing the adult with IDD from receiving the vaccination. This points to a potential need for greater respect for autonomy and supportive decision making around COVID-19. In addition, the role of support staff needs to be evaluated to assure their actions align with the wishes of the care partner/guardian and adult with IDD.

Further work needs to be done to determine how additional COVID-19 decisions are being made by individuals with IDD (e.g., boosters, etc.) as well as other health decisions. Learning from and adapting to barriers to receiving the vaccination is critical as vaccinations and boosters continue to be made available. In identifying barriers, participants also suggested solutions such as providing vaccinations in locations that were accessible to or commonly used by adults with IDD. Strategies such as these are emerging by partnering with community organizations such as DD Councils and Special Olympics to translate COVID-19 information and provide vaccination opportunities. The current work also suggests a

need to further investigate the relationship between QoL and vaccination status and attitudes, as it appears that QoL may be playing an important role in whether individuals with IDD feel confident in the safety of the vaccination and actually receive it. Better understanding those relationships may help us target information that addresses individuals' concerns with vaccinations and overall hesitancy.

Although QoL was initially found to be higher in the 2017 cohort than in the 2021 cohort, subsequent models that included various covariates indicated that reporter was a better predictor of QoL. Care partners reported higher QoL than self-reporters, and the only predictor of QoL in the full model with all covariates was age (younger people had higher reported QoL than older people across time points). This is in line with previous work in the general population that has shown that, in general, QoL decreases with age.³¹ The sample also included a significantly higher number of care partners reporting on QoL, particularly in 2021, as compared to self-report. Future work must prioritize capturing QoL data directly from adults with IDD to ensure an accurate representation of their lived experience and its influence on QoL.¹⁹ Although adults with IDD exhibit lower QoL than their peers without IDD, there is also important variability amongst individuals with IDD.³² More work is necessary to fully understand the nuances of QoL within IDD populations, in particular in times of crises such as the COVID-19 pandemic when it is even more important to hear directly from people with IDD to ensure their needs are being addressed.

In contrast to our hypothesis, the current study did not find differences between the reported satisfaction with the amount or quality of services between 2017 and 2021. The COVID-19 pandemic created complex temporary and permanent impacts on service access and delivery for people with IDD including impacts related to changes, adaptation, and diversification of services and supports provided and how they are delivered.³³ It is possible that the lack of differences pre- and during-COVID-19 could be due to the sampling of the study. For example, it is likely that the individuals that completed these online surveys have more access to online resources and networks, and thus may have already had more services prior to COVID-19 and/or were able to maintain services through COVID-19 through use of telehealth services compared to non-study participants. Still, future research should look more into the values of "quantity" versus "quality," and how satisfied receivers of services are, with the support they are receiving, instead of simply the amount of services they receive.

The current study was limited in that the Longitudinal Long-term Care Survey is anonymous; thus 2017 and 2021 data was not able to be linked. While some individuals may have completed the survey at both time points, we cannot make within-person comparisons across time. Additionally, care partner participants in this unique sample were not matched to self-reporters. Because individuals could either report for themselves or have a care partner participate on their behalf, we only have one reporter (self or care partner) for each case. Thus, reporter comparisons should be interpreted with caution, as it is likely that there are distinct differences in the disability characteristics of those who self-reported compared to those for whom someone else reported on their behalf. Further, we did not collect detailed information about participants' clinical diagnoses or diagnostic characteristics. An important limitation is the reliance on single-item measures of quality of life and satisfaction with the amount and quality of care received. Both quality of life and care satisfaction are complex, multidimensional constructs. Future research should dive deeper into the nuances of these subjective constructs by using validated measures, such as the World Health Organization's Quality of Life measure.³⁴ In addition, linear regression models were fitted to predict Likert responses to questions; thus the dependent variable was ordinal, not continuous. Results should therefore be interpreted with caution. Finally, the racial diversity of the sample was somewhat limited, with 80 % of the sample of adults with disabilities being white. However, the sample did have slightly greater racial diversity representation than in the state of Wisconsin where the data was collected.

5. Conclusion

The current study highlights opportunities that can inform and shape service delivery and future pandemic response planning. It is important, particularly during times of societal crises, to identify effective ways to involve adults with IDD in the decisions being made for them and about their lives, and to monitor service and supporter responses to ensure that the voices and wishes of adults with IDD are being elevated and respected. Future work should include larger samples of self-reporting adults with IDD and multiple informants for the same individual to better understand and compare QoL from multiple perspectives within the lives of adults with IDD. Further, more work needs to be done to determine other ways to measure these constructs in ways that allow for more participation of individuals with IDD. In our study, many individuals with IDD reported high quality of life and high care satisfaction and QoL was linked with a greater likelihood of receiving a COVID-19 vaccine. More work is needed to understand the experiences of those who report low quality of life and lack of satisfaction with care and potential implications for health and health care access.

Declaration of competing interest

The authors declare that they have no conflict of interest.

Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.dhjo.2023.101545>.

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