Perceptions of discrimination and intervention services by Asian and Asian-American caregivers of children with disabilities throughout the duration of COVID-19

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Perceptions of discrimination and intervention services by Asian and Asian-American caregivers of children with disabilities throughout the duration of COVID-19

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Abstract

Coronavirus-19 (COVID-19) had large impacts on the daily lives of many in the United States from 2020 to 2023. COVID-19 caused country-wide school closures starting in the spring semester of the 2019-2020 school year. Closures had a particularly significant impact on children receiving special education services. In addition, COVID-19 had an impact on Asian-American families with many reporting an increase in Anti-Asian discrimination due to the origin of the COVID-19 virus. However, it was not known if Asian-American families experienced increases in discrimination that may have impacted their children's special education services or if their experiences with special education services and discrimination changed as the pandemic continued. Therefore, participants who identified as Asian or Asian-American were recruited to complete an anonymous, 10–15-minute survey using the NIU Qualtrics platform. The questionnaire included questions about participants’ background demographics, the types of special education services their child received in 2020 and 2023, how COVID-19 affected their child’s access to intervention and their perceived quality of those services, and caregiver’s experiences with discrimination. Preliminary reports about one family’s experience with special education services and Asian discrimination during COVID-19 indicated that the pandemic did not have a significant impact on that family’s access to and satisfaction with their child's special education services. They reported a small disruption in special education services at the beginning of the pandemic that was resolved by 2023. This caregiver's perception of discrimination was low before the COVID-19 pandemic, but they reported a slight increase in discrimination at the beginning of the pandemic that decreased from 2020 to 2023. Although more participants are necessary to draw further conclusions, it’s important to understand how
Introduction

Coronavirus disease 2019 (COVID-19) is a disease caused by the SARS-CoV-2 virus. It spreads if you breathe in small droplets and particles that contain the virus or if these droplets or particles enter your eye, nose, or mouth. Symptoms of COVID-19 include flu-like symptoms such as fever, cough, muscle, or body aches, and can further develop into pneumonia and death (CDC, 2021). Because COVID-19 spreads easily, it was quickly classified as a global pandemic as it spread from Wuhan, China to the entire world. As of January 2023, there have been 664,873,023 confirmed cases of COVID-19 and 6,724,248 deaths due to COVID-19 globally (WHO, 2023). The United States (U.S.) has recorded the second highest total confirmed cases (184,161,028 cases) (WHO, 2023).

Unfortunately, in 2020 as cases of COVID-19 in the U.S. rose, so did anti-Asian sentiments and hate most likely related to the Asian origin of COVID-19 and rhetoric on social media repeatedly referring to COVID-19 as the “Chinese virus”. Prominent leaders, including our former president Donald Trump, used specific and damaging language such as “Chinese virus” that were some of the catalysts of anti-Asian movements that “…likely perpetuated racist attitudes,” (Reja, 2021). The Federal Bureau of Investigation documented a 76% increase in hate crimes against Asian people in the U.S. Compared to 158 reported incidents in 2019, reported hate crimes against those of Asian descent rose to 279 in 2020 (Barr, 2021).
Alongside a rise in anti-Asian hate, COVID-19 also affected many aspects of daily life. For example, COVID-19 had a large impact on the U.S. education system. In the U.S., COVID-19 caused country-wide school closures starting in the spring semester of the 2019-2020 school year (Education Week, 2020). The impact was particularly significant for children receiving special education services. The U.S. Centers for Disease Control (CDC) conducted a survey with the state coordinators of early intervention services in the fall of 2020. Their focus was on low-income Black and Latino families with limited English proficiency. The study revealed that in 2020 overall referral rates for special education services dropped, there were longer wait times for an evaluation, and fewer children received early intervention services among Black and Latino families (The Education Trust, 2021). Additionally, the CDC conducted an assessment identifying the impact of COVID-19 on early identification and special education services. The study found that most respondents (91%) reported that the COVID-19 pandemic “highly impacted” early identification for developmental delays and disabilities for children (CDC, n.d.). These studies provide evidence that special education services were impacted by Covid-19, but they do not provide information about how special education services for Asians and Asian-Americans were specifically impacted.

There is some information from other sources about how special education services were impacted for Asian American populations. A study conducted by Dababnah, Kim, Wang, and Reyes (2021) concluded that, in a sample of 25 participants, one out of three were affected from COVID-19 closures in the areas of academics, therapy services, and recreational activities. Nearly half of families reported struggles finding alternate forms of activities and services during the height of the pandemic. Only two families expressed satisfaction with telehealth while the rest were more dissatisfied. Although this study provided insight on the Asian-American
population, it still lacked a long-term view of the effects of COVID-19 because it only measured family’s perspectives at one point in time in 2020. It is not known if family’s perspectives changed. Therefore, one purpose of the current study is to understand how COVID-19 affected caregivers’ perceptions of access to and the quality of their children’s therapy services in 2020 and determine if there were changes in their perceptions as the pandemic progressed.

It is also possible that the increasing anti-Asian sentiment after COVID-19 caused Asian-American caregivers of children receiving special education services to be even more impacted by the COVID-19 global pandemic than other caregivers. However, Dababnah, Kim, Wang, and Reyes (2021) reported that most families felt less fearful of discrimination at the start of the pandemic. They suggested their findings could be influenced by many different factors, including being secluded in one’s own home during lockdown and having fewer interactions outside the family than before the pandemic. A study conducted by Woo, Maglalang, Ko, Park, Choi, and Takeuchi (2021) surveyed Korean and Filipino families in two waves. It concluded that parental experiences of racial discrimination in 2020 increased their teachings of caution about racial barriers and discussions about being ready for future challenges. Additionally, a study by Cheah, Zong, Cho, Ren, Wang, Xue, and Wang (2021) surveyed Chinese adolescents and their self-identified Chinese parents. They concluded that if a person had low bicultural identity integration (i.e., how a person perceptualizes disconnect vs. overlap between two cultures), they were more vulnerable to the effects of COVID-19, including feelings of racial discrimination. Although these studies touched upon discrimination sentiments at the beginning of the pandemic, it is unknown how experiences with discrimination changed as the pandemic continued and as discrimination may have become less in the forefront of the people’s minds and in the news. Therefore, it is important to determine if, as time has gone by and the effects of
COVID-19 decreased, if the impact of the pandemic in 2023 has the same impact on Asian-American family’s perception of discrimination as it did in 2020. It is also not known how Asian-American family’s perceptions of discrimination might be related to their satisfaction with their child’s special education services.

Although there have been many studies investigating the effects of COVID-19, there are no studies asking families about the effects of the pandemic overtime on Asian-American's perceptions of special education services. Therefore, this study aimed to examine Asian and Asian-American caregivers’ perceptions of access to and quality of their children’s intervention services and if those perceptions changed from 2020 to 2023. It also aimed to understand how Asian and Asian-American caregivers of children with disabilities perceived discrimination at the start of the pandemic and if those perceptions changed as the pandemic progressed. It was hypothesized that perceptions of discrimination would be high at the beginning of the pandemic but would improve in 2023 and perceptions on access to and quality of special education services would initially be low but also improve in 2023.

Method

Participants

Participants were recruited who met the following criteria: at least 18 years old, identified as Asian, have a child of school-age (4-18 years old), and have a child diagnosed with a speech, language, and/or developmental disability. The survey was sent to many different organizations within Illinois. This included religious organizations, schools, children with disabilities advocacy centers, and Asian/Asian-American support organizations. Additionally, flyers were distributed
around the Northern Illinois Campus and by word of mouth. Despite an intensive recruitment period, only 1 participant completed the survey. That caregiver identified as Asian and Filipino. Their highest level of education was a college degree. Their child was 14 years old with diagnoses of developmental delay, hearing impairment, orthopedic impairment, and speech or language impairment. The child received 1-3 session(s) of physical therapy within the last month in-person in 2020 and 2023.

Procedures

Survey

One participant completed a 10–15-minute anonymous survey on the secure NIU Qualtrics platform asking them about any experiences with discrimination during COVID-19 and their perceptions of their child’s special education services. The questions used a 6-point Likert scale with the following parameters: Strongly disagree, disagree, somewhat disagree, somewhat agree, agree, and strongly agree. A 6-point scale was used to allow for flexibility and to give caregivers a variety of answers to choose from so any patterns and trends could be more easily visualized. Additionally, it also required the participant to be decisive on their thoughts because it did not include a neutral middle answer. For the full survey, see appendix A.

The first block of the survey included 6 questions relating to background demographics of the participant and their child. Questions included indicating their race, ethnicity, highest level of education, and verifying if they have a school-aged child with a speech, language, or developmental disorder and specifying the disorder(s). After the completion of this set of questions, caregivers completed a set of 7 questions to get more information about the types of
services their child received in 2020 and 2023, and how often they received those services within the past month. The final question set included questions about how COVID-19 affected their child’s intervention and their perceptions of discrimination. There were 3 questions asking caregivers to compare services in 2020 to 2023 and their current overall feelings about intervention services. Next, there were 2 questions asking about changes in participant’s feelings of discrimination with a child with a disability. The last set of questions included 3 questions about participants experiences with discrimination for being Asian and if their perceptions of discrimination changed overtime as the COVID-19 pandemic progressed.

Results

Reports from one family's experience with special education services and Asian discrimination during COVID-19 indicated that the pandemic did have moderate impact on that child's access to special education services. From Figure 1., the caregiver slightly agreed with COVID-19 affecting their child’s ability to obtain quality intervention. However, in 2023 this was resolved, as the caregiver disagreed that COVID-19 still affected their ability to obtain quality intervention. When asked if the caregiver preferred services in 2020 versus 2023, the caregiver responded “disagree”, meaning the caregiver preferred the services they are receiving in 2023. As for discrimination sentiments, this caregiver's perception of discrimination was low before the COVID-19 pandemic, but they felt a slight increase in discrimination at the beginning of the pandemic by stating “slightly agree” to the prompt, “I noticed an increase in discrimination against myself/my child at the beginning of the pandemic. This later decreased from 2020 to 2023 as their answer shifted from “slightly agree” to “disagree” when asked if they
noticed a steady increase in discrimination from 2020 to 2023. The caregiver reported never feeling discriminated against because their child had a disability.

Figure 1.

*Singular Caregiver’s Reports of Discrimination and Special Education Services During the COVID-19 Pandemic*
Discussion

Results from the singular caregiver who completed the survey supported the first hypothesis. It was hypothesized that there would be an increase in disruptions in special education services at the beginning of the pandemic that would decrease overtime. The singular participant “agreed” that COVID-19 affected their child’s ability to receive services in 2020, but “disagreed” when asked if COVID-19 is still affecting their services in 2023. Additionally, this caregiver preferred services in 2023 over 2020. This suggests that although there were disruptions at the beginning of the pandemic in terms of access to services and quality of services, these issues were resolved in 2023. From this study, service access and quality had been impacted the most from COVID-19, more than feelings of discrimination due to the pandemic. Findings from the current study are similar to Debabnah, Kim, Wang, and Reyes (2021) who reported that many families were negatively affected by community closures due to COVID-19 in the areas of academics, therapy services, and recreational activities. Families reported their largest struggle was finding alternate forms of activities and services in the height of the pandemic. Although COVID-19 did affect their child’s access to and the quality of services, this family still attended in-person physical therapy sessions in 2020 and 2023 and so their dissatisfaction in 2020 could stem from COVID-19 protocols like social distancing and wearing masks. Most schools and facilities removed those precautions by 2023.

However, results from the singular caregiver who completed the survey did not support the second hypothesis. It was hypothesized that caregivers at the beginning of the pandemic would have high levels of feelings of discrimination, which would decrease overtime but still be evident in 2023. The caregiver reported no feelings of discrimination for having a child with a disability. Also, the caregiver felt little discrimination for being Asian at the beginning of the
pandemic but reported even less by 2023. When the caregiver was asked if they felt discrimination for having a child with a disability before and during the pandemic, the participant responded with disagreement for both. Additionally, when asked if they noticed an increase in discrimination for themselves or their child at the beginning of the pandemic, they responded only with “slightly agree.” Afterwards, they marked disagree with seeing an increase in discrimination in 2023, noting that their perceptions of discrimination decreased since 2020. In the study conducted by Debabnah, Kim, Wang, and Reyes (2021), they drew similar conclusions. Contrary to our hypothesis, families in their study also reported lower amounts of discrimination for being Asian-American at the start of the pandemic. Being discriminated against was also not a prominent fear in the minds of the families that they surveyed. The authors suggest that could have been because families were secluded in their own homes during lockdown and had fewer interactions outside the family than before the pandemic (Debabnah, Kim, Wang, & Reyes, 2021). These similar suggestions could help explain the feelings of the participant in the current study.

Unfortunately, conclusions cannot be made from this study because to date only one caregiver has completed the survey. The response of one caregiver cannot be extrapolated to other caregivers who identify as Asian-American. Although it is good to note that the caregiver has felt very little feelings of discrimination, that may not be the experience of other Asian-American caregivers. There could be many factors that could have swayed the emotions of the caregiver at the time of taking the survey. For example, we don’t know how much time they spent outside of the house at the height of the pandemic, where the family lives, and what other resources were available for them. To increase the applicability of the results, additional participants will be recruited to gather a wider range of experience, thoughts and opinions from
Asian and Asian American caregivers. It would also be wise to broaden the search for participants to other regions within the nation, especially areas with high concentrations of Asians and Asian Americans, to gain better chance of families who fit the criteria of the study.

References


Appendix A

Qualtrics Survey

Q1. Please Indicate your race: (Check all that apply)

☐ American Indian/Native Alaskan

☐ Asian

☐ Black or African American

☐ Native Hawaiian other Pacific Islander

☐ White

☐ Other ____________________________________________

Q2. Please indicate your ethnicity: (Check all that apply)

☐ Chinese

☐ Filipino

☐ Indian

☐ Vietnamese

☐ Korean

☐ Japanese
☐ Pakistani
☐ Cambodian
☐ Hmong
☐ Thai
☐ Laotian
☐ Bangladeshi
☐ Indonesian
☐ Nepalese
☐ Other ____________________________

Q3. Please indicate your highest level of education:

☐ Some High School
☐ High School Graduate
☐ Some College
☐ College Degree
☐ Graduate Degree
Q4. Do you have a child 4 years or older who has ever been diagnosed with a developmental, language, or speech disorder?

○ Yes

○ No

Q5. Which ones? (Check all that apply)

☐ Autism

☐ Deaf-Blindness

☐ Deafness

☐ Developmental Delay

☐ Emotional Disability

☐ Hearing Impairments

☐ Intellectual Disability

☐ Multiple Disabilities

☐ Orthopedic Impairment

☐ Other Hearing Impairment

☐ Specific Learning Disability
☐ Speech or Language Impairment
☐ Traumatic Brain Injury
☐ Visual Impairment

Q6. How old is your child?

☐ 3 Years or Younger
☐ 4 Years
☐ 5 Years
☐ 6 Years
☐ 7 Years
☐ 8 Years
☐ 9 Years
☐ 10 Years
☐ 11 Years
☐ 12 Years
☐ 13 Years
☐ 14 Years
☐ 15 Years
☐ 16 Years
☐ 17 Years
Q7. Within the last month, what services, if any, did your child receive? (Check all that apply)

☐ Speech Therapy
☐ Physical Therapy
☐ Occupational Therapy
☐ Social Work

Q8. In 2020, how did your child receive intervention? (Check all that apply)

☐ In-Person
☐ Online
☐ Combination of in-person and online
Q9. In 2023, how did your child receive intervention? (Check all that apply)

- [ ] In-Person
- [ ] Online
- [ ] Combination of in-person and online

Q10. Within the last month, how many times did your child receive SPEECH AND LANGUAGE SESSIONS?

- [ ] 1-3 Session(s)
- [ ] 4-6 Sessions
- [ ] 7-9 Sessions
- [ ] 10+ Sessions

Q11. Within the last month, how many times did your child receive PHYSICAL THERAPY SESSIONS?

- [ ] 1-3 Session(s)
- [ ] 4-6 Sessions
- [ ] 7-9 Sessions
- [ ] 10+ Sessions
Q12. Within the last month, how many times did your child receive OCCUPATIONAL THERAPY SESSIONS?

- 1-3 Session(s)
- 4-6 Sessions
- 7-9 Sessions
- 10+ Sessions

Q13. Within the last month, how many times did your child receive SOCIAL WORK SESSIONS?

- 1-3 Session(s)
- 4-6 Sessions
- 7-9 Sessions
- 10+ Sessions

Q14. In 2020 at the beginning of the pandemic, COVID-19 affected my child’s ability to obtain intervention that meets their needs.

- Strongly agree
- Agree
- Somewhat agree
- Somewhat disagree
Q15. Now, in 2023, the pandemic affects my child’s ability to obtain intervention that meets their needs.

- Disagree
- Strongly disagree
- Strongly Agree
- Agree
- Somewhat Agree
- Somewhat Disagree
- Disagree
- Strongly Disagree

Q16. I am happier with the services my child received in 2020 than I am now in 2023.

- Strongly Agree
- Agree
- Somewhat Agree
- Somewhat Disagree
- Disagree
- Strongly Disagree
Q17. BEFORE the pandemic, I felt discriminated against for having a child with a disability.

- Strongly Agree
- Agree
- Somewhat Agree
- Somewhat Disagree
- Disagree
- Strongly Disagree

Q18. DURING the pandemic, I felt an increase in discrimination for having a child with a disability.

- Strongly Agree
- Agree
- Somewhat Agree
- Somewhat Disagree
- Disagree
- Strongly Disagree

Q19. I have felt discriminated against for being Asian.

- Strongly Agree
- Agree
- Somewhat Agree
Q20. I noticed an increase in discrimination against myself/my child at the BEGINNING of the COVID-19 Pandemic.

- Strongly Agree
- Agree
- Somewhat Agree
- Somewhat Disagree
- Disagree
- Strongly Disagree


- Strongly Agree
- Agree
- Somewhat Agree
- Somewhat Disagree
- Disagree
- Strongly Disagree