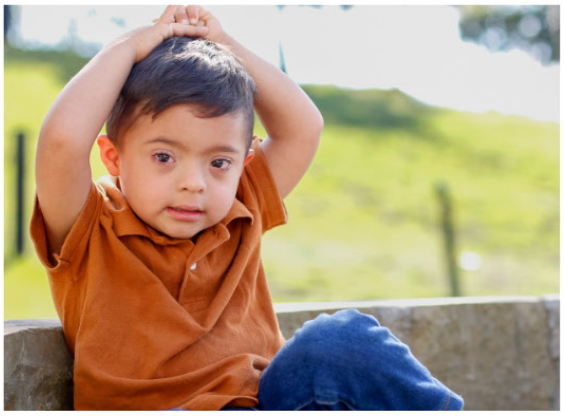
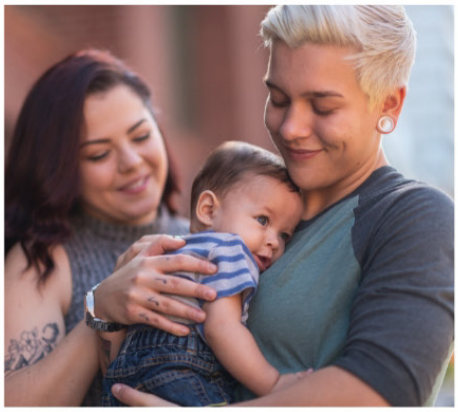
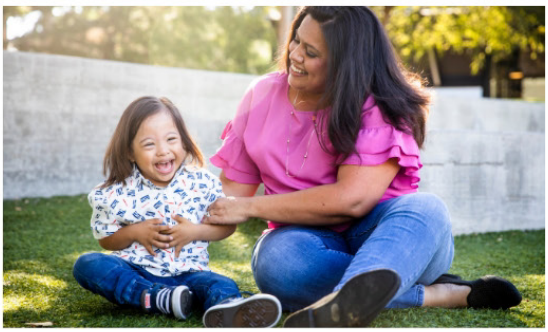
2022-2023

CHILD FAMILY SURVEY (CFS)
PHONE MODE PILOT REPORT

National Core Indicators®-Intellectual and Developmental Disabilities (NCI®-IDD)
Report on Telephone Pilot Test Administration of the CFS in the State of Texas





Introduction

National Core Indicators®-Intellectual and Developmental Disabilities (NCI®-IDD) is a collaborative effort between the National Association of State Directors of Developmental Disabilities Services (NASDDDS) and the Human Services Research Institute (HSRI). The purpose of the program, which began in 1997, is to support state developmental disabilities (DD) service systems to gather a standard set of performance and outcome measures that can be used to track their own performance over time, to compare results across states, and to establish national benchmarks. NCI-IDD is dedicated to collecting information on critical life outcomes, service experience and satisfaction directly from those receiving services and their families.

One category of surveys in the NCI-IDD survey portfolio is Family Surveys. These surveys are traditionally completed on paper ("mail") or over the internet ("direct entry"). These surveys are completed by families of people receiving services from their state DD system and aim to assess the family experience. One such survey is the Child Family Survey (CFS). Respondents to the CFS are families that have a child under age 18 living with them and receiving at least one service (in addition to case management) from the state DD system.

States that opt into participating in the CFS can choose how to design their sample, with guidance from HSRI. States can either sample from the eligible sample or distribute the survey to all eligible families. Typically, the survey is mailed to the sample along with a self-addressed, stamped envelope to facilitate return. Along with the survey, states can include information on how to access the survey online ("direct entry") if that is the respondent's preference. Once the mailed surveys are returned, they are entered into the Online Data Entry System Administrator (ODESA), HSRI's proprietary survey data collection platform. When surveys are entered directly online using the direct entry option, the responses are automatically saved into the ODESA portal.

States often follow up with potential respondents to encourage participation.

Amidst decreasing response rates and concerns about representativeness of the final samples, the NCI-team worked with the state of Texas to pilot test audio telephone administration of the survey.

The pilot test endeavored to answer the following research questions.

1) Did the phone respondents differ significantly from non-phone (mail or direct entry) survey respondents in demographic factors and personal characteristics that are likely to impact the representativeness of the data?
2) Were there mode differences in the responses to survey questions beyond what would be expected from the surveys' margins of error? For example, did people responding via

phone respond differently to specific questions when compared to those who responded via non-phone?

3) Is the phone mode valid and reliable for administration of the family surveys?
4) In what ways can the mode differences be minimized by refining the protocols (e.g., revised scripts for introducing the survey to respondents, ways to help respondents understand the response options without reading them every time) and surveyor trainings (e.g., strategies for setting up and controlling the survey environment, establishing rapport, and maintaining focus during phone surveying).

Methods

Sample

The Texas Department of Health and Human Services contracted with the University of Florida to administer the surveys. HSRI gave specific instructions to the pilot team on how the pilot would be conducted.

The pilot team was asked to pull their CFS sample. It was determined that the sample would be pulled from the population of families who have a child enrolled in STAR Kids program and who lives in the family home and receives at least one service other than case management from the state DD agency. The total sample frame was 12,066 families at the time of the sample selection. The sample was stratified by managed care organization (MCO), yielding nine strata. Within each stratum, 60% of families were randomly assigned to the phone and 40% to the mail/direct entry modes. This resulted in a total of 7,143 families in the phone sample and 4,825 families in the mail/direct entry sample. The ODESA portal included a data field identifying the mode of each survey record.

The pilot team noted that the state's access to phone numbers would not differ systematically for different populations. They did not suspect that the randomly selected "phone" population would differ significantly in demographics or personal characteristics from the randomly selected mail/direct entry population in any way. Star KIDS service users' records are updated regularly.

The pilot team was instructed to keep note of the number of phone attempts made, and the final "disposition," including detailed information on the reason for survey non-completion (if applicable). Disposition information was available for 7,117 of the families assigned to the phone sample.

Paper and Direct Entry Survey Administration

The pilot team was instructed to mail the survey instrument to those randomly assigned to the mail/direct entry mode. These participants had the option of responding on paper and mailing the completed survey to the pilot team or entering their responses directly into the data portal.

Phone Survey Administration

Surveyors called the sampled phone numbers and made multiple attempts in cases where the first attempt failed to reach the participant. Whenever possible, they left a message requesting a callback; if the participant was reached but preferred a different time for the interview, they made an appointment. If the person refused to participate in the survey, no further attempts were made.

Many phone surveyors were bilingual (English/Spanish). When the surveyors called to schedule the interview, families were offered the option to complete the survey right then on the phone, or to complete the survey over the phone at a later set time. If the surveyor spoke both English and Spanish and the family wanted to complete the survey right then, the family was able to do that. If the surveyor didn't speak Spanish and the family wanted to conduct the interview in Spanish, a later appointment was scheduled and a Spanish-speaking surveyor was assigned.

Survey Tool Modifications

HSRI prepared a modified CFS survey tool (including Texas state-specific questions) to facilitate a seamless, conversational survey over the phone. The survey tool included elements such as scripts to introduce sections, explicit instructions regarding what could be read to the respondent, instructions on how to deliver response options and more. The modified survey tool also included feedback questions for the respondent and surveyor regarding their experiences with the phone mode.

The pilot team then added their state-specific consent language (which is not required for the mail or direct entry versions) to the introductory "script" and translated the phone survey tool into Spanish.

The mailed survey and accompanying cover letter were sent to all families in English and Spanish.

Surveyors and Surveyor Training

The pilot team subcontracted with another entity to conduct the phone survey.

Along with contributions from the pilot team, HSRI developed and conducted a [length] surveyor training. The training included elements such as:

1) Description of NCI-IDD, the purpose of the CFS, and how the data will be used.
2) Survey etiquette and establishing rapport.
3) Script and wording for the initial call. For example, the training included instructions to ask for the "caregiver of [child's name]" or "the person who knows most about [child's name]." The training also included information on how to explain the survey and purpose to respondents.

4) How to schedule the survey for the future versus how to conduct the survey immediately.
5) How to proceed if the respondent needs an interpreter.
6) State consent process.
7) Mandated reporting, incident reporting, and recording/reporting unmet need.
8) Entering survey responses into ODESA
9) How to administer survey – for example, when to read responses, and not to give other examples/definitions that aren't provided in the tool.
10) How to do the surveyor/respondent feedback forms and what to add as comments.

Institutional Review Board Determination

The IRB at HSRI determined that the pilot of the phone mode did not require IRB oversight because the project did not meet the definition of "research" according to 45 CFR 46. The IRB at HSRI considers the evaluation of the new survey mode to be a Quality Assurance and Quality Improvement (QA/QI) project, and is not designed to contribute to generalizable knowledge, and, as such, is not considered research.

Data analysis

Disposition of Phone Contacts

Overall, during the survey administration, 80,499 calls were made to complete the CFS known to be attempted with 7,117 potential respondents. Included in the final dataset used for analysis are 927 surveys that were conducted by phone. That is a completion rate of 13%. On average, it took 4.6 calls to complete a survey. Table 1 demonstrates the final dispositions as reported by the survey team.

Table 1: Final dispositions for phone surveys

Category of final disposition	Final disposition	Number of potential respondents
Survey complete	Complete, Complete-Spanish, consented cell phone	927 (13.0%)*
No contact made	Busy, no answer after 6 rings, no ring, disconnected number, all circuits busy, temporary failure, requested circuit not available, fax/modem/data line, ring no answer, cell does not accept incoming calls, number not in service	1023 (14.4%)
Contact made, no response	Answering machine, mailbox is full, mailbox is not set up yet, disconnected	3909 (54.9%)
Response, refusal	Refusal, hostile refusal, "take me off the list," hung up during introduction	438 (6.2%)
Ineligible	Ineligible, Out-of-Scope: Business/Government, Out-of-Scope: Dorm/Prison/Hostile/Institute, Out-of-Scope: Other	106 (1.5%)
Other	Technical circumstances, case review—not finalized, Fast busy, General call back, language line, language changed-Spanish, Soft appointment, Hard appointment, Respondent will call 800 line	814 (11.4%)

**This is based on the final number of surveys included in our analysis. The other numbers in this table come from the list of Final Dispositions provided to us by the state. Some of the completed surveys have a different reported disposition, which is why the numbers do not add to 100%.*

Difference in response rate

The overall response rate was 10.5%. The response rates between the modes (phone vs. mail/direct entry) are not comparable because multiple attempts were made to achieve complete phone surveys. An average of 4.6 calls were made for each completed phone survey. Additionally, we don't have access to final disposition data on the mail/direct entry surveys, so it isn't clear what proportion of the mail/direct entry non-responses were due to inaccurate contact information.

Feedback from phone surveyors and phone respondents

As mentioned, the phone survey included questions eliciting feedback from the participant and the surveyor on the experience of the phone mode. Between 700-800 participants provided feedback on the phone mode. Between 700 and 850 surveyors provided feedback on the phone survey mode. Here are some of the results from those feedback forms:

Respondent feedback

- 67% of respondents who provided feedback ("feedback respondents") reported that on a scale of 1-5 (1=easy), the experience of taking the survey by phone was 1. (N=766). The mean response was 1.7.
- Over half of the feedback respondents (52%, N=732) reported at least one factor that made the survey hard to complete. 21% reported that the length of the survey made it hard to complete, and 19% reported that the questions were hard to answer, and 23% were distracted by things happening around them.
- When asked "If you were to take this survey again, would you prefer to do the survey by phone again, on paper or over the internet," 49% of feedback respondents said they would prefer the internet/paper. (N=739)
- Open field comments communicated by feedback respondents related to the phone mode included:
    - "Some questions are too long; I got lost"
    - "Hard to do on the phone between 'yes' and 'always' [response options]"
    - "It was easy to talk and explain my answers"
    - "Didn't like the call dropping"
    - "The answer options (e.g., always, usually) are too long; wish the answer options were no more than 3"
    - "Cannot retain long questions"

Surveyor feedback

- 34% of surveyors who provided feedback ("feedback surveyors") reported that the surveyor and respondent had difficulty hearing each other for at least some of the questions. (N=808)
- 24% of feedback surveyors reported that the questions were difficult to say/pronounce over the phone. (N=804)
- 27% of feedback surveyors reported that they observed or thought that the participant did not feel comfortable answering all of the questions (N=805)
- 32% of feedback surveyors reported that they observed or thought that the participant had difficulty paying attention during the survey (N=801)
- 12% of feedback surveyors reported that there were issues with technology that made it hard to conduct the survey such as spotty connection and/or difficulty hearing (N=804)
- According to phone surveyors' feedback, the average length of a survey was 39 minutes. Mail/direct entry respondents, on the other hand, reported an average survey length of 26 minutes. The difference is statistically significant (independent samples t-test $p<0.001$)
- Open field comments communicated by feedback surveyors related to the phone mode included:
    - "Difficulty understanding dialect"

- "Had difficulty hearing the respondent," "Respondent had echo," "The quality of the connection wasn't good," "She sounded like she was far away," "Lots of background noise"
- "Respondent was distracted"
- "Respondent kept interrupting"
- "Questions were long and I had to restate for respondent"
- "Respondent thought the same question was being asked several times"
- "Some questions did not apply making the survey unnecessarily long"
- "Questions too long with options ... By time finish offering responses he forgot the question"
- "Respondent kept pausing and talking to someone else or getting quiet"
- "She left the phone for time period (put me on hold)"
- "Respondent fell asleep"

Bivariate Comparisons of Participant Characteristics and Responses

We assume that the populations approached to participate in the CFS by phone and those approached by mail were randomly selected and therefore there are no significant differences in the populations. However, the populations of those who complete surveys using the phone or mail/direct entry do differ. The differences are likely due to different response rates of the two samples.

Table 2: Demographic and personal characteristics that differ by survey mode (Z-Test for difference between two proportions, p<.05)

Demographic/Personal characteristic	Phone	Mail/direct entry
There is more than one child in the household	72.0%	59.5%
Child has diagnosis of autism spectrum disorder (for example, autism, Asperger syndrome, pervasive developmental disorder)	42.8%	34.7%
Child has been diagnosed with Oral health or dental problems that cause ongoing pain or difficulty eating	20.6%	11.7%
Child's race/ethnicity: Black or African American	19.6%	9.3%
Child's preferred language: English	92.2%	85.4%
Child's preferred language: Spanish	5.6%	12.4%
Respondent's age: under 35	19.2%	10.5%
Respondent's age: 55 to 74	10.9%	18.8%
Respondent's health: Very good	22.4%	32.9%

Demographic/Personal characteristic	Phone	Mail/direct entry
Respondent's health: Poor	7.6%	3.1%
Respondent's highest education level: High school diploma or GED	23.0%	16.7%
Respondent's highest education level: Vocational school or certificate program	4.6%	9.8%
Total income last year of all wage earners in household: $50,001-$75,000	8.3%	13.0%
Total income last year of all wage earners in household: Over $75,000	15.4%	23.8%
Total income last year of all wage earners in household: No earned income	13.2%	8.9%
Total income last year of all wage earners in household: Prefer not to say	23.4%	15.2%
Family receives financial support: money (cash, stipends, vouchers, or reimbursement) to purchase items, equipment, or needed services This does NOT include SSI payments	9.0%	14.3%
Child receives early intervention services	35.0%	6.9%
Child receives services or supports from other agencies or organizations (school services, vocational rehab, etc.)	49.9%	59.9%

All responses are self-reported by the respondent. Missing and don't know responses were excluded from the denominator for this table.

There are also several characteristics by which the phone and mail/direct entry populations did not differ.

Table 3: Demographic and personal characteristics that did not differ by survey mode

Gender of child
Child has diagnosis of ID, mental illness, cerebral palsy, limited or no vision, hearing loss (severe or profound), brain injury, seizure disorder and/or neurological problem, chemical dependency, down syndrome, Prader Willi syndrome, FASD
Child has diagnosis of cardiovascular disease, diabetes, cancer, high blood pressure, high cholesterol, dysphagia, pressure ulcers, sleep apnea, other pulmonary diagnosis, asthma, chronic kidney disease, long COVID-19
Child's race is American Indian or Alaska Native, Asian, Pacific Islander, White, Hispanic/Latino,
Child's primary means of communication
Child's support needs to manage self-injurious, disruptive, or destructive behavior
Child's support needs with daily personal care activities
Language usually spoken at home
Respondent's relationship to child
Respondent or other family member paid to provide support to child
Number of adults in the household
Rural or urban
Family receives in-home support, respite care, early intervention, transportation, Mental/behavioral health care or other treatments or therapies, self-direction/fiscal intermediary services

Differences in responses and response patterns between phone and mail/direct entry respondents

We looked at differences in responses and response patterns between phone and mail/direct entry in two ways.

Differences in responses or skipping question (missing and "don't know" responses are included in the denominator). The first way we looked at differences in responses was to examine the breadth of significant differences in responses when missing data and "don't know" responses were included in the denominator. "Not applicable" responses were excluded from the denominator because they were often the result of legitimate skip patterns and don't often represent a respondent's choice.

Of 88 questions in the standard CFS survey tool, 84 showed significant differences ($p<=.05$) in responses between the phone and non-phone respondents when missing data and "don't know" responses were included in the denominator.

Of the 65 questions that did not offer multi-select responses, 42 (64.6%) had a significant mode difference in the percent of respondents leaving the question blank, resulting in missing data ($p<0.05$). In those 42 cases, the phone respondents were more likely than the mail/direct entry respondents to leave the question blank.

Of the 65 questions that did not offer multi-select responses and had "don't know" as an available response option, 47 (72.3%) had a significant mode difference in the percent of respondents selecting that option ($p<0.05$). In all 47 cases, mail/direct entry respondents were more likely than phone respondents to select the "don't know" response.

Differences in responses when only valid responses are included in the denominator (excluding missing, don't know and not applicable from the denominator). We then examined the breadth of significant differences in responses while excluding missing, don't know and not applicable responses.

Of 88 questions in the standard CFS survey tool, 45 showed significant differences ($p<=.05$) in responses between the phone and non-phone respondents when missing data, "don't know" responses and "not applicable" responses were **not** included in the denominator. This demonstrates that the mode differences in "missing" and "don't know" responses are not driving all of the mode difference we are seeing in responses.

Differences in rates of responding "Always" or "Seldom/Never." In examining the data, we found that phone respondents were more likely to respond "always" or "seldom/never" when presented with the "Always," "Usually," "Sometimes," "Seldom/never" response options. For 22

out of 28 questions that used this Likert scale, phone respondents were significantly more likely (p<=.05) to have selected the first or last options ("always" or "seldom/never") when compared to the mail or direct entry respondents, who were more likely than phone respondents to have chosen the middle options ("usually" or "sometimes"). This may indicate that the Likert scale does not translate well to phone administration. A possible reason for the difference could be that the "extreme" options may be easier to recall compared to the more nuanced options in the middle of the list. This notion is supported by surveyor and participant feedback that it was difficult to remember all of the response options if there were too many. Further cognitive testing may be needed to test whether responses collected over the phone using this Likert scale are comparable to responses collected via mail or direct entry.

Differences in number of questions answered. We found that there were differences in how many questions people answered in the survey based on phone versus non-phone response mode.

For this analysis, we determined the numbers of questions with missing data for each case. We then conducted ANOVA tests to assess whether the number of questions with missing data was statistically significantly different between the groups. We found that overall, the difference in average numbers of questions with missing data was significantly different. This was most likely driven by the difference occurring in the survey portion of the survey, which may indicate that phone respondents (who had, on average, more questions with missing data) were more likely to drop off earlier in the survey.

Table 4: Questions with missing data

Mode	**Average number of questions missing data from the entire data record** (p<.001)	**Average number of questions missing data from the demographics section**	**Average number of questions missing data from the survey portion** (p<.001)
Phone	23.35	5.41	17.94
Not phone	18.75	6.20	12.55

Discussion

Through examination of the surveyor and respondent feedback data, we see that respondents rated the experience of doing the survey by phone as relatively easy. However, qualitative information indicated numerous barriers, challenges, and frustrations related to the phone mode such as distraction, communication difficulties, length of survey questions, and the length of the survey itself. There were also differences in completion rate, with mail/direct entry respondents having significantly fewer questions with missing data in the later portions of the survey, potentially indicating that phone respondents were more likely to end their surveys before they were complete.

Results of the pilot study of the phone mode of administration of the Child Family Survey indicate that there were significant differences between the personal and demographic characteristics of respondents who answered by phone, and those that responded by mail/direct entry. Although we are unsure the impact of these differences on the representativeness of the data, we believe that these differences merit further examination.

Furthermore, there were significant mode differences in the actual responses to the survey questions and the rates of missing data and “don’t know” responses. These differences encourage us to ask whether the survey, as it is written, can translate well from being administered visually to auditorily.

Other mode differences that merit further exploration include:

- How the Likert scale we used functions in phone survey mode versus non-phone mode.
- What influences a respondent's decision to select "don't know" as a response to a question versus a respondent's decision to skip the question altogether. ("Don't know" responses significantly differed by mode on almost all survey questions.)
- How people respond when speaking to a surveyor over the phone versus how they respond when filling the survey independently and anonymously. (Does fear of judgement influence the formulation of responses in phone mode?)

Disposition data also indicated that a large amount of effort was made to complete the phone surveys; surveyors made an average of almost 5 calls to each survey respondent before the survey could be completed.

Conclusions

Based on this study, we do not believe that NCI-IDD should proceed with administration of the family survey via phone mode until further testing and research is done to examine:

1) The different characteristics and demographics of the populations who respond via phone and mail/direct entry and how those characteristics might influence the differences in survey responses.
2) The impact of responding directly to the surveyor over the phone, when compared to responding independently and anonymously by mail or direct entry.
3) What is influencing differences in response based on mode, specifically for the questions that present a Likert scale (with response options “always,” “usually,” “sometimes,” “seldom/never”) and how we can mitigate those differences. Mitigation of differences may include:
    a. Changing response options for both the phone and mail/direct entry tool.
    b. Enhancing surveyor training on how to convey the applicable response options for each question.
4) Why there is a mode difference in “don’t know” responses and skipped questions.
5) What is the overall impact of mode on the amount of data collected through the surveys.
6) Strategies for surveyors to ensure phone respondents complete the survey at similar rates to those who participate via mail/direct entry.
7) Strategies for phone surveyors to minimize distractions and facilitate uninterrupted survey administration with respondents.
    a. This may include strategies for setting up and controlling the survey environment, establishing rapport, and maintaining focus during phone surveying.

The NCI team will consider how to approach these research questions in upcoming years.

For questions, please Dorothy Hiersteiner: dhiersteiner@hsri.org

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