



Waukesha County
Department of Health and Human Services

2020 Children with Special Needs
Consumer Quality Assurance Survey



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Executive Summary

At the request of and in cooperation with the Waukesha County Department of Health and Human Services (DHHS), in 2021, **Neighborhood Analytics, LLC** analyzed the results of the 2020 wave of the ongoing Children with Special Needs (CSN) Consumer Quality Assurance Survey and compiled this report.

The CSN Consumer Quality Assurance Survey was developed in 2016 by the Special Services Advisory Committee, which is made up of community providers, parents, and CSN staff. Neighborhood Analytics, LLC was contracted to administer the survey beginning in 2017; previous to that, it was administered by CSN staff. The survey is sent annually to the parents/guardians of every child who received services from the CSN unit within that calendar year (households that received services for >1 child receive one survey for each child). The survey seeks to measure satisfaction with several dimensions of service coordinator performance, perceptions of parent/guardian involvement, perceptions of outcomes, and preparedness for transition to adult services.

In 2020, 666 mail surveys were distributed to valid addresses; 114 completed surveys were returned, yielding a response rate of 17%. By comparison, the response rates for the 2019, 2018, 2017, and 2016 waves were 17%, 18%, 17%, and 24% respectively. The industry-standard return rate for mailed paper surveys is ~10%.

Each survey question consists of a statement which respondents are asked to indicate agreement or disagreement with on a 5-point scale ranging from “strongly disagree” (1) to “strongly agree” (5). For each question, the average response is presented, along with the overall distribution of responses across answer categories. Apples-to-apples comparisons across years (made possible by identical question wording across years) are also presented when possible. The past two waves also included a question that asked each respondent to identify the age range of the relevant minor child; this allows for comparison of responses across age cohorts. This most recent wave included a question battery aimed at understanding supplemental service provision.

Major Findings

- Aggregate satisfaction with multiple dimensions of service coordinator performance remain high and relatively stable over time.
- Average levels of satisfaction with service coordinator and program effectiveness continue to increase incrementally, building on a three-year trend.
- Perceived self-involvement in service plan development/outcomes remains high, and has remained relatively stable across the past five waves.
- The proportion of respondents indicating that their child/family experienced severe health and/or safety concerns while waiting for services is at the lowest point in five years.
- Most respondents with children who were 17 as of July 1st 2019 said they are prepared for transition to adult services, and the majority continue to agree that their service coordinator had assisted with preparation. However, survey responses suggest that preparedness for transition may be decreasing relative to past years.
- Gaps in sentiment across respondents with children in different age groups grew in 2020; respondents from families with older children are significantly more satisfied with service coordinator performance and program effectiveness when compared to respondents from families with younger children.
- Participation in external programs and receipt of outside services are associated with differences in opinion regarding CSN programs and service coordinator performance. Those with informal community and/or in-home providers and those who participated in parent support groups are most likely to have different opinions about CSN programs and services.

A Note on Methodology

While an attempt is made to collect survey data from every eligible member of the population under study, in practice only a subset return completed surveys. During analysis of the resulting data, observed changes over time or observed differences across groups are subjected to statistical tests in order to determine whether or not they are “real”; in other words, whether or not we would actually see these changes or differences had we been able to collect perfect, complete data from every single individual in the population under study. Such statistical testing is necessary because any time you are attempting to learn about a population by examining a subset of it, there is the possibility of error due to the subset not being a perfectly representative slice of the population.

For many decades, social scientists labeled an observed change or difference as “statistically significant” as long as the estimated probability of avoiding such error was 95% or higher. While large observed changes or differences are more likely to be statistically significant, not all statistically significant changes are large or even substantively important. Indeed, statistical significance alone says nothing about the magnitude, meaningfulness, or importance of an observed change or difference. Statistical significance merely indicates a very high likelihood that a change or difference observed in a sample would also be seen in the population under study had every individual been measured.

In recent years, there has been a movement among data scientists and statisticians to stop using this arbitrary 95%-or-higher standard and instead directly report for every item the estimated probability that an observed change or difference would still be seen if the entire population had been directly measured. This allows the reader to judge for herself or himself the degree to which an observed change or difference should be taken seriously.

In this report, any time a possibly meaningful change or difference is presented, we follow the guidelines mentioned above and report the estimated probability that it would be seen had we been able to collect complete data from the entire population under study. For each such item, associated statistical values and coefficients used to calculate these estimated probabilities are recorded in a separate footnote.

Full Results

Question one asked respondents to agree or disagree with the following statement: *“I am involved in the development of my child’s Service Plan and Outcomes.”* Figure 1a shows that the average response (4.7) was closest to “strongly agree,” and that the average response to this question has remained relatively stable over time. Figure 1b shows no substantively important change in the distribution of responses between this wave and the last.

Figure 1a

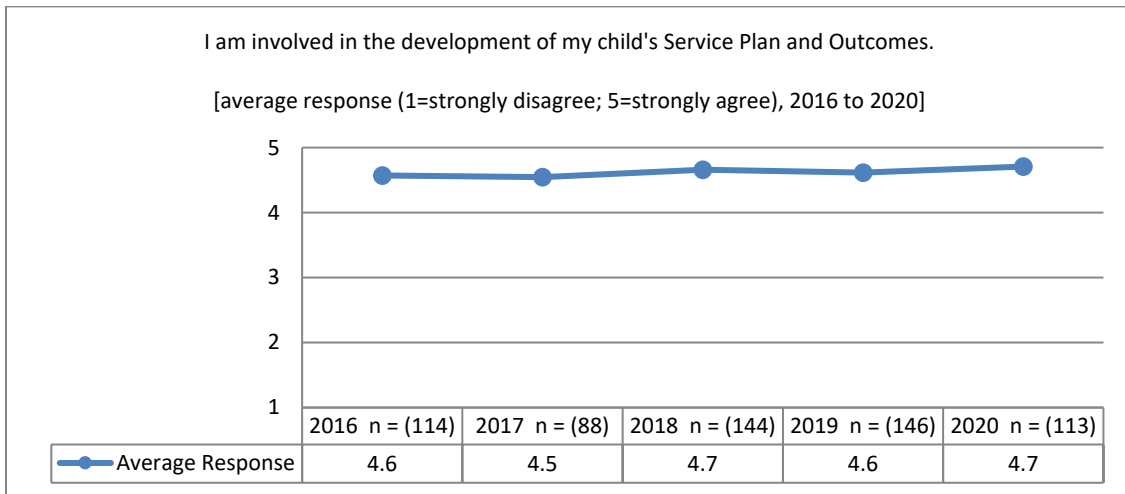
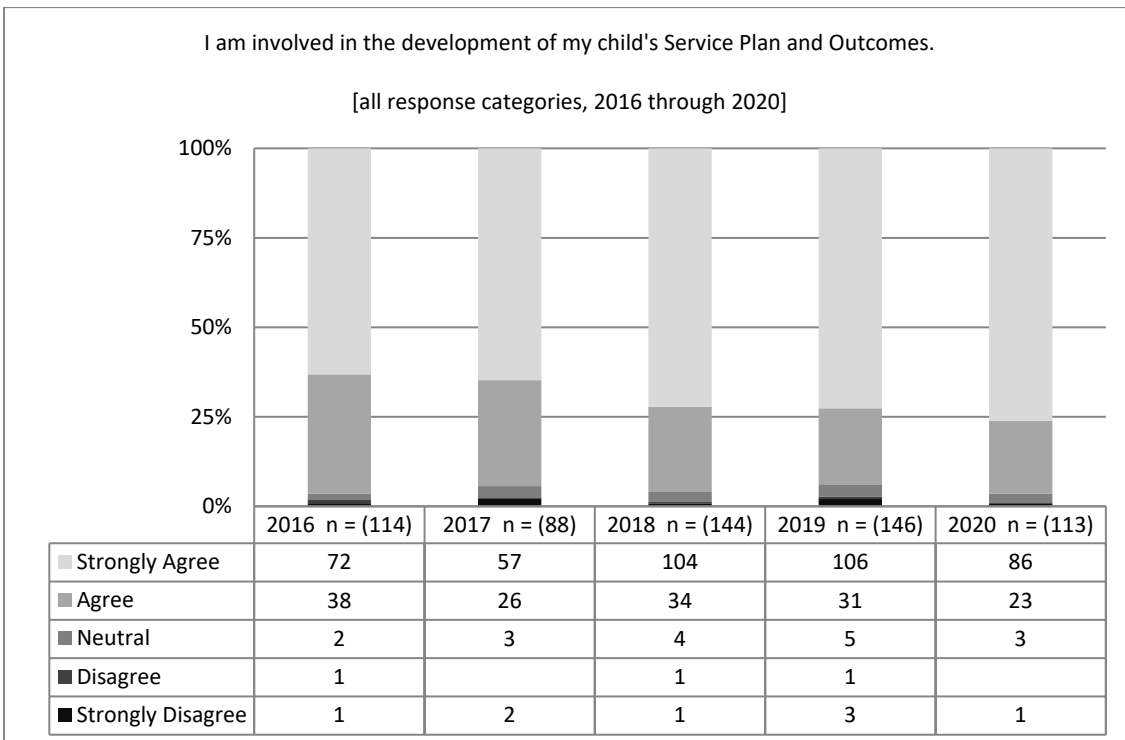


Figure 1b



The **second question** asked respondents to agree or disagree with the following statement: ***“I am provided with useful feedback, information, and resources in relation to my child’s needs.”*** Figures 2a and 2b show that the average response (4.1) is closest to “agree”, and that the both the average response and the overall distribution of responses have remained constant over the past five years.

Figure 2a

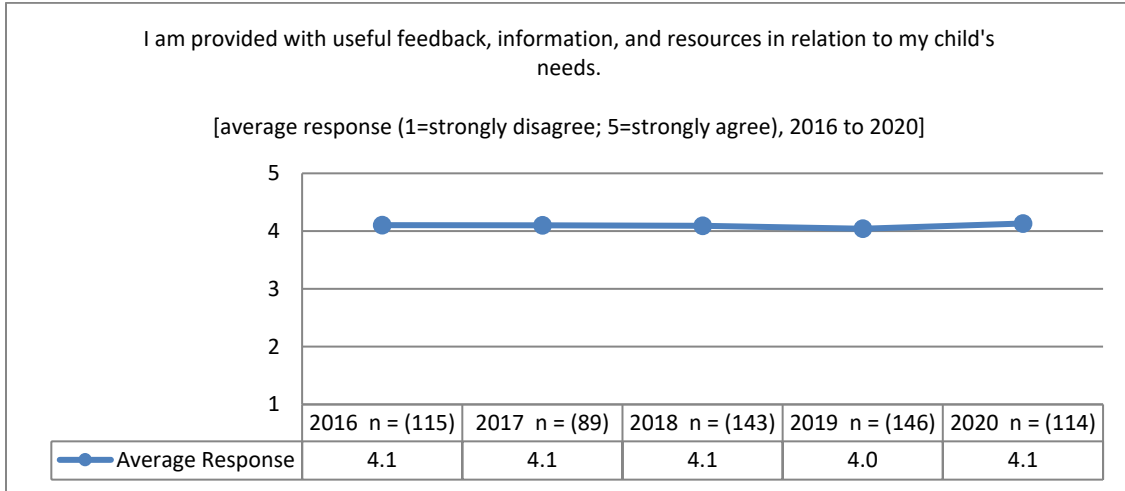
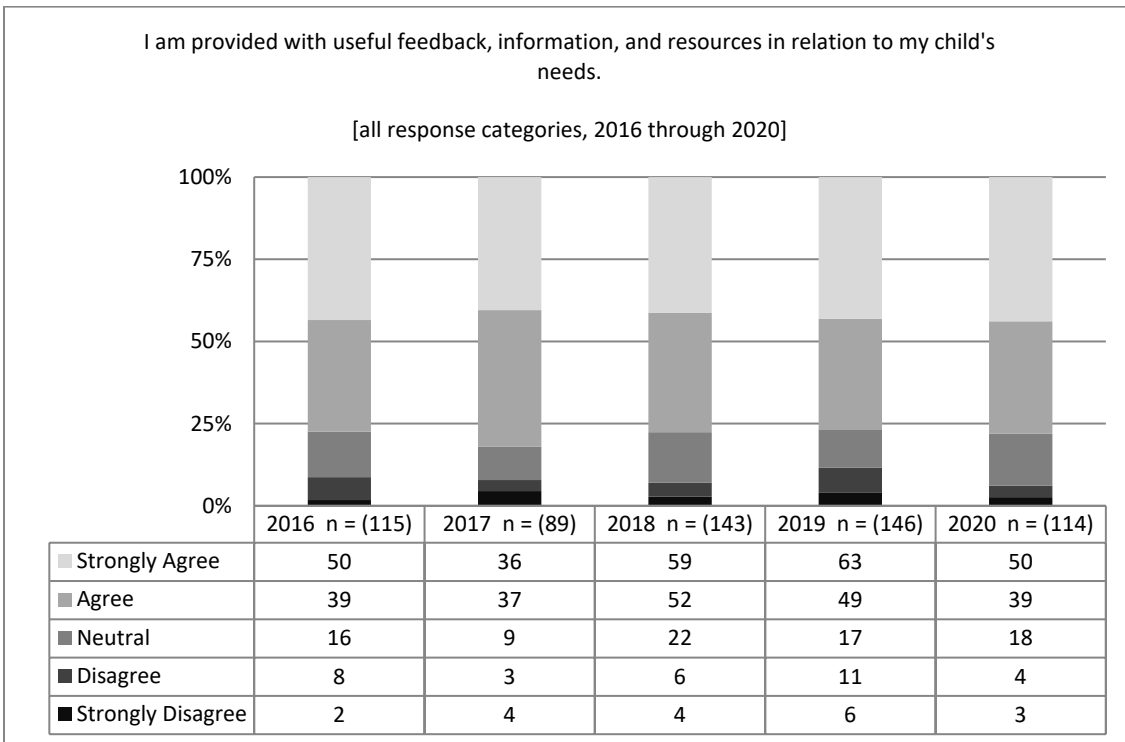


Figure 2b



Question three asked respondents to agree or disagree with the following statement: *“My service coordinator helps me to better understand the abilities and limitations for the programs that we are currently participating.”*

Figure 3a shows that the average response (4.1) is closest to “agree”, and that the average level of agreement has not changed over the last four years. Figure 4b, however, shows a shift in the underlying distribution of responses. After a 3-year trend of increasing polarization, where incremental increases in the proportion of respondents stating “strongly agree” were offset by simultaneous increases in the proportion of respondents saying “strongly disagree”, this year there has been depolarization. The larger proportion of respondents answering in the middle range (54% in 2020, compared to 46% in 2019) is indicative of more consistency relative to this dimension of service coordinator performance across respondents. A statistical test against this change cannot be performed, however, because of the small sample size.¹

Figure 3a

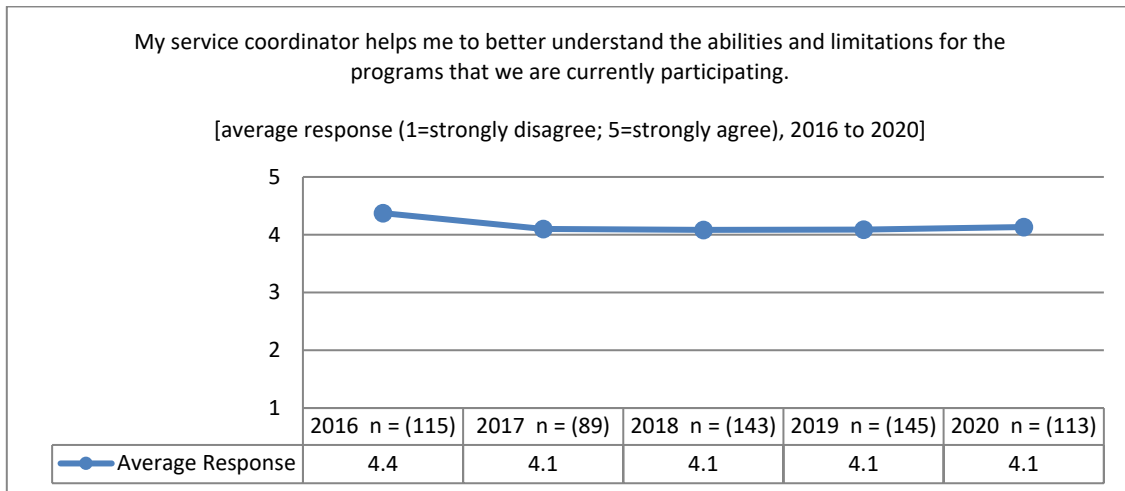
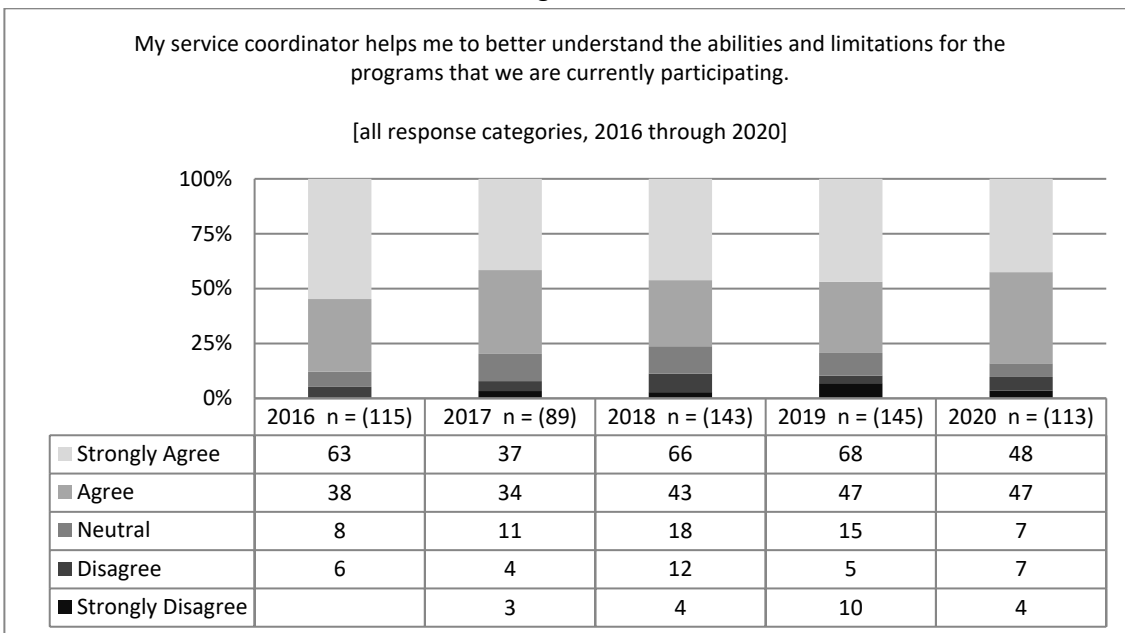


Figure 3b



¹ Chi-squared test estimates are unreliable when the *n* within individual cells is less than 5.

The fourth question asked respondents to agree or disagree with the following statement: ***“My requests, questions, and concerns are responded to in a timely manner.”*** Figure 4a shows that the average response (4.4) is closest to “agree”. The average level of agreement with this statement has increased slightly over the past four years. Figure 4b shows a small, gradual accompanying positive shift in the distribution of responses during this time period.

Figure 4a

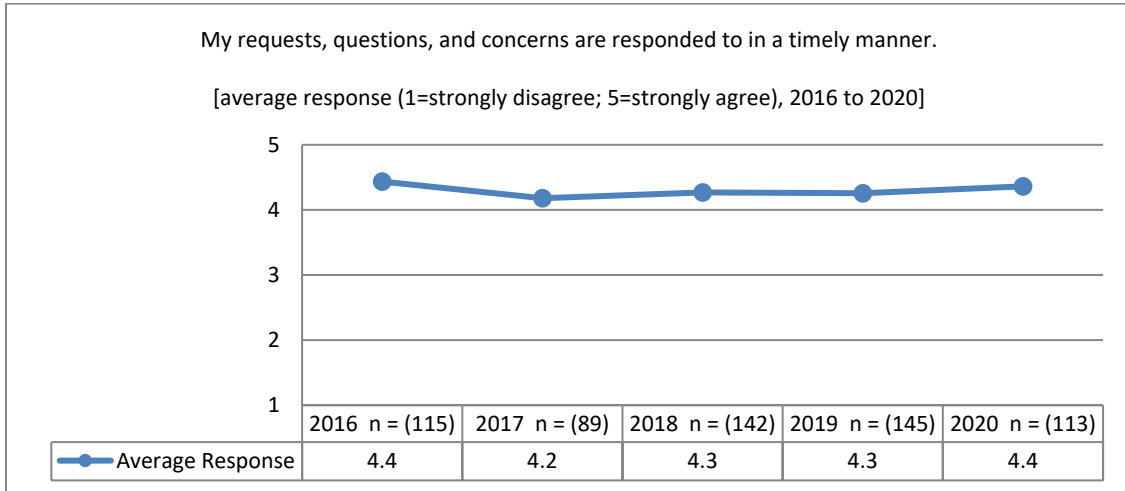
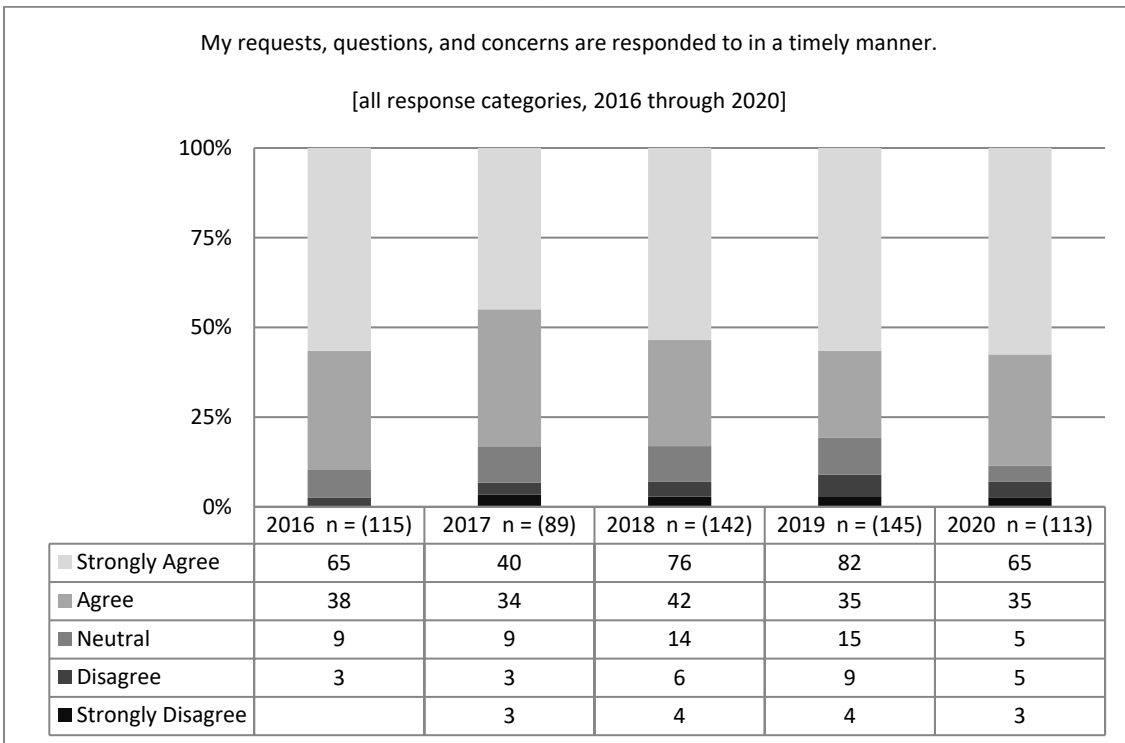


Figure 4b



Question five asked respondents to agree or disagree with the following statement: *“Follow-through to my requests, questions, and concerns are appropriate.”* Figure 5a shows that the average response (4.4) is nearest to “agree”; a slight positive change in sentiment for the third year in a row after a sharper negative change in 2017. There is a 95% probability that the observed increase between 2017 and 2020 would be still be seen had every member of the population under study been measured.² Figure 5b shows incremental positive change in the distribution of responses during the same period, with more respondents indicating they “strongly agree” over each of the past three years.

Figure 5a

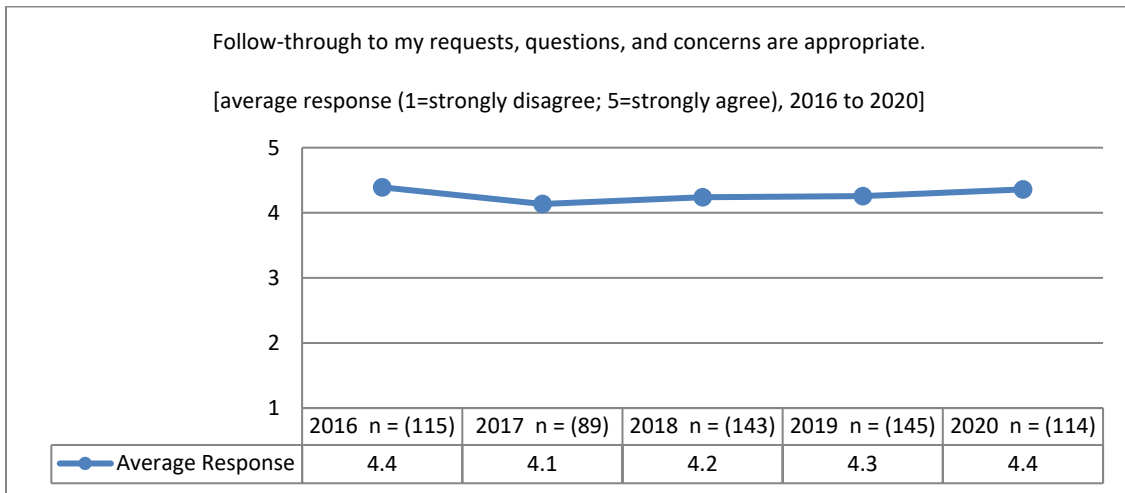
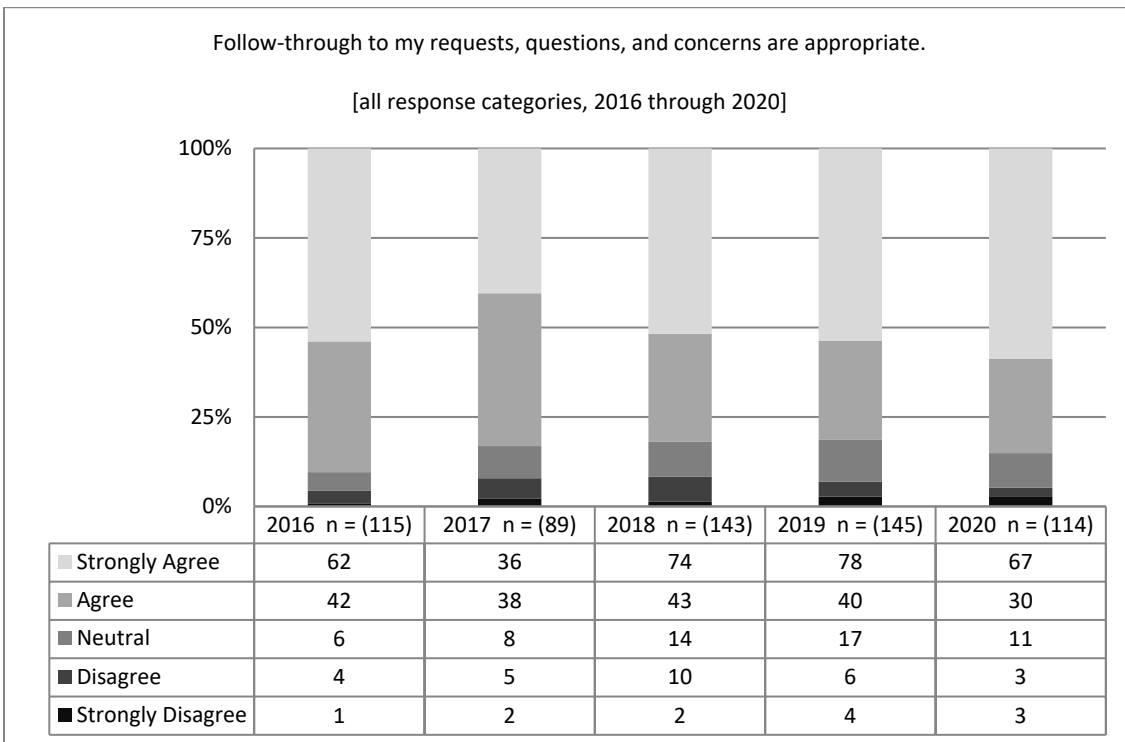


Figure 5b



² $t = 1.67$, $df = 201$, $Pr(T > t) = 0.05$

The sixth question asked respondents about their agreement or disagreement with the following statement: ***“My service coordinator assists in meeting the needs of my child and family.”*** Figure 6a shows the average response (4.3) is closest to “agree”. The average level of agreement has increased incrementally over the last three years following a dip in 2017; however, changes to the distribution of underlying responses highlighted in Figure 6b are inconsistent and do not follow a clear pattern.

Figure 6a

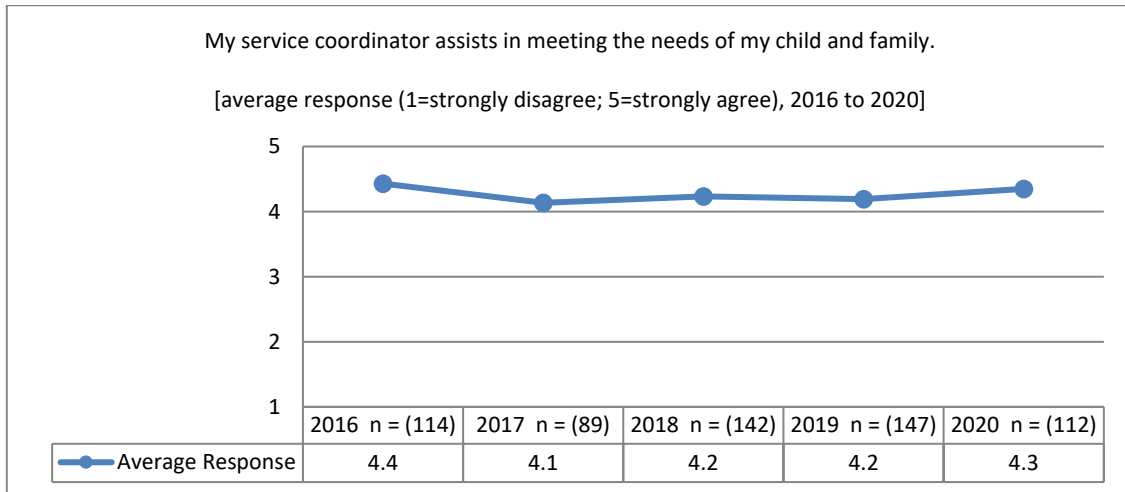
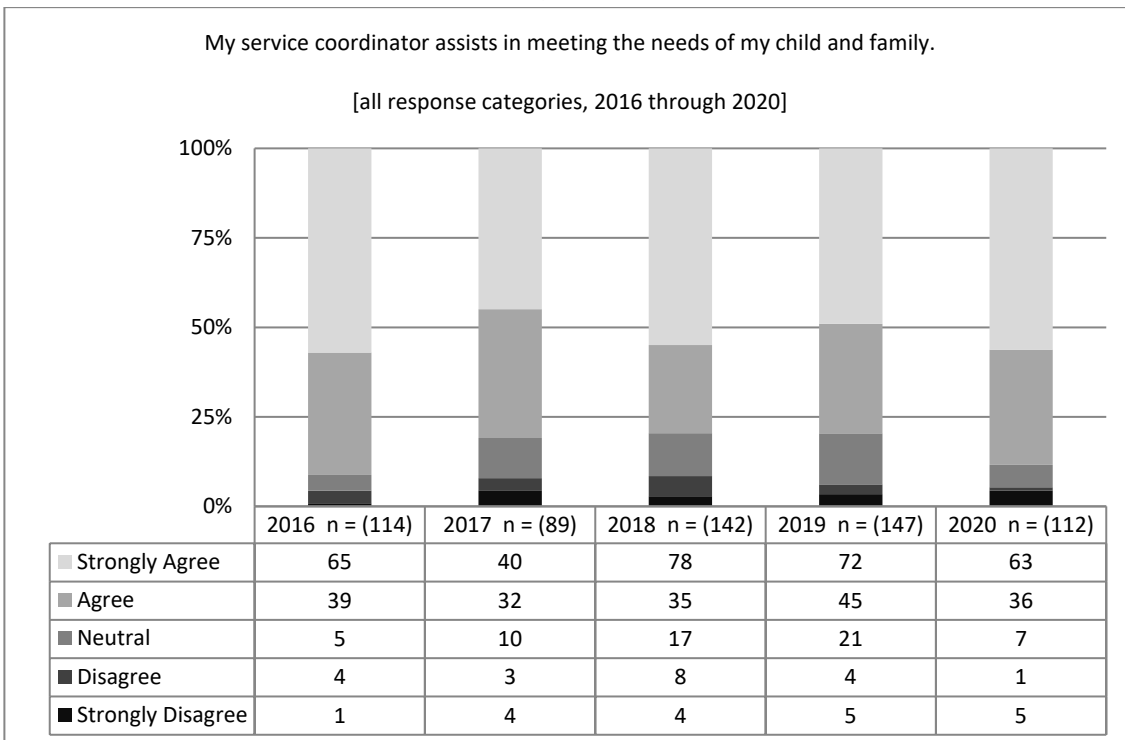


Figure 6b



Question seven asked respondents to agree or disagree with the following statement: *“I am satisfied with the amount of time my service coordinator is available to my family.”* Figure 7a shows that the average response (4.4) is closest to “agree”. The average level of agreement with this statement has increased after two years of relative stability; there is a 97% chance that this increase between 2019 and 2020 would be seen if every relevant member of the populations of interest had been measured.³ Figure 7b shows that this change in average sentiment was driven by a notable reduction in the proportion of respondents saying they “disagree” or “strongly disagree”.

Figure 7a

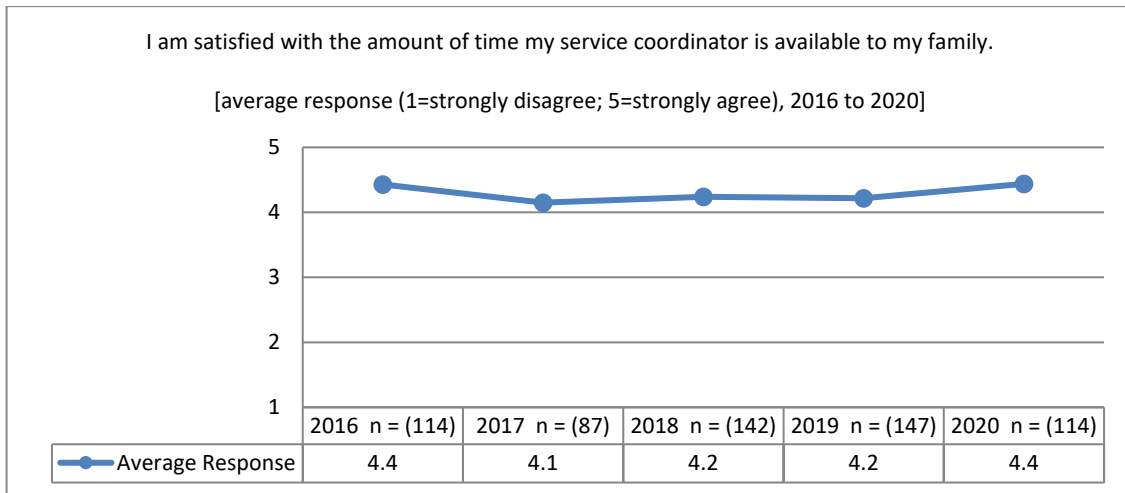
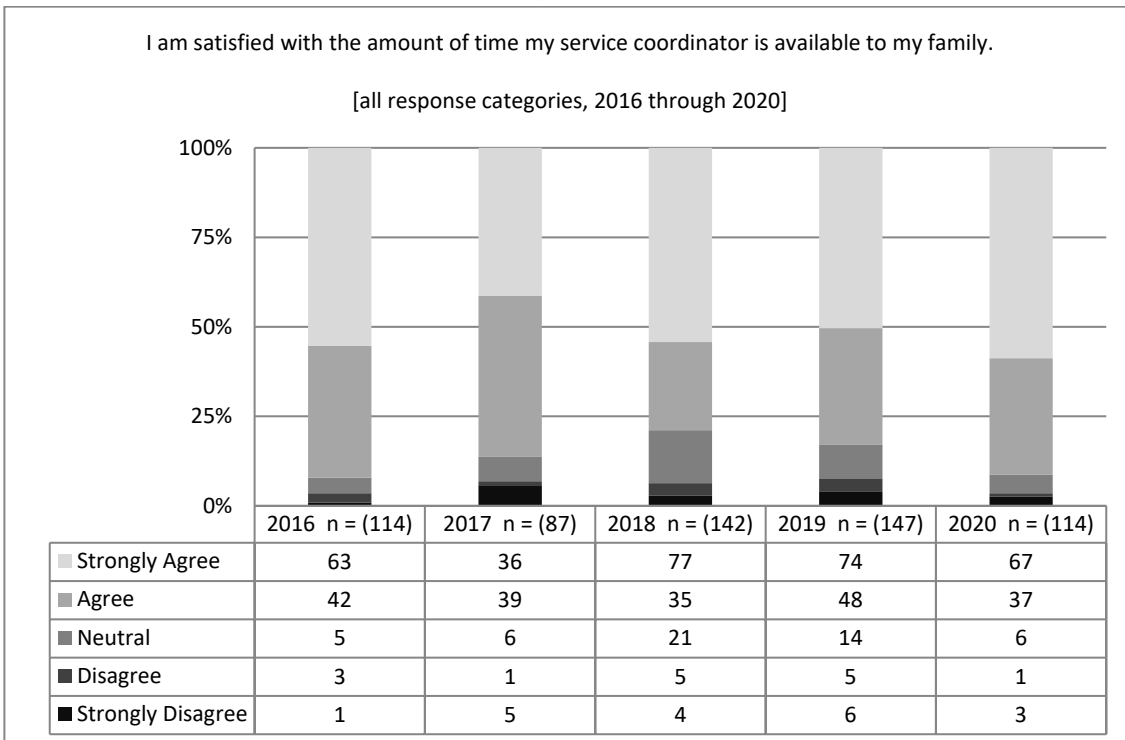


Figure 7b



³ $t = 1.85$, $df = 259$, $Pr(T > t) = 0.03$

The **eighth question** asked respondents to agree or disagree with the following statement: ***“[My child was 17 years old as of July 1st 2019] My service coordinator has provided me assistance with the transition to adult services process.”*** Figure 8a (page 12) shows that the average response to this item (4.0) is closest to “agree”, and that this represents a negative change in sentiment that has persisted for two years. While the number of responses for 2019 and 2020 for this question are very small, statistical testing indicates there is 74% probability that a negative change of this magnitude would still be observed had we been able to collect data from every member of the population under study.⁴

Figure 8b (page 12) shows a shift in the distribution of responses between 2018 and 2019; however, due to the low number of observations, statistical testing of distribution changes is unreliable.⁵ While it is very likely that there has been a negative overall shift in the distribution of sentiment regarding this item in the population under study, it is not possible to get more specific about the nature of the underlying changes based on this data.

Comparisons of this wave against 2016 and 2017 results for this question are not recommended, as survey question wording changed in 2018. Where previous waves of this survey asked for responses from those whose “child is close to turning 18,” starting in 2018 the survey began asking for responses only from those whose children were 17 years old as of July 1st of the previous year. This change dramatically decreased the proportion of respondents who provided a response, from ~38% in 2017 down to ~7% in 2018. It is very likely that the striking positive changes to the average response and the overall distribution of responses between 2017 and 2018 are due to a smaller and more objectively defined eligibility requirement for answering the question.

⁴ $t = -0.66$, $df = 9$, $\Pr(T > t) = 0.27$

⁵ Chi-squared test estimates are unreliable when the n within individual cells is less than 5.

Figure 8a

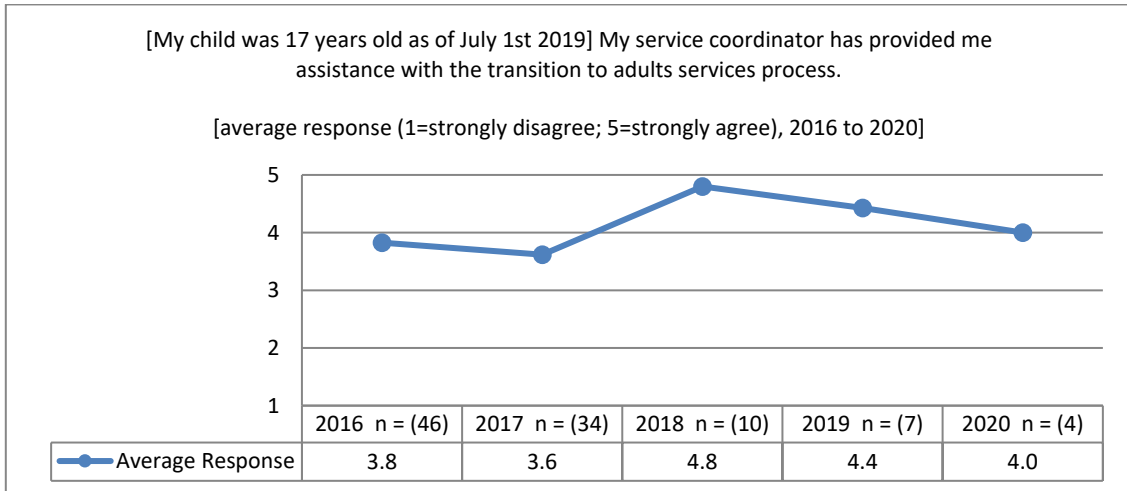
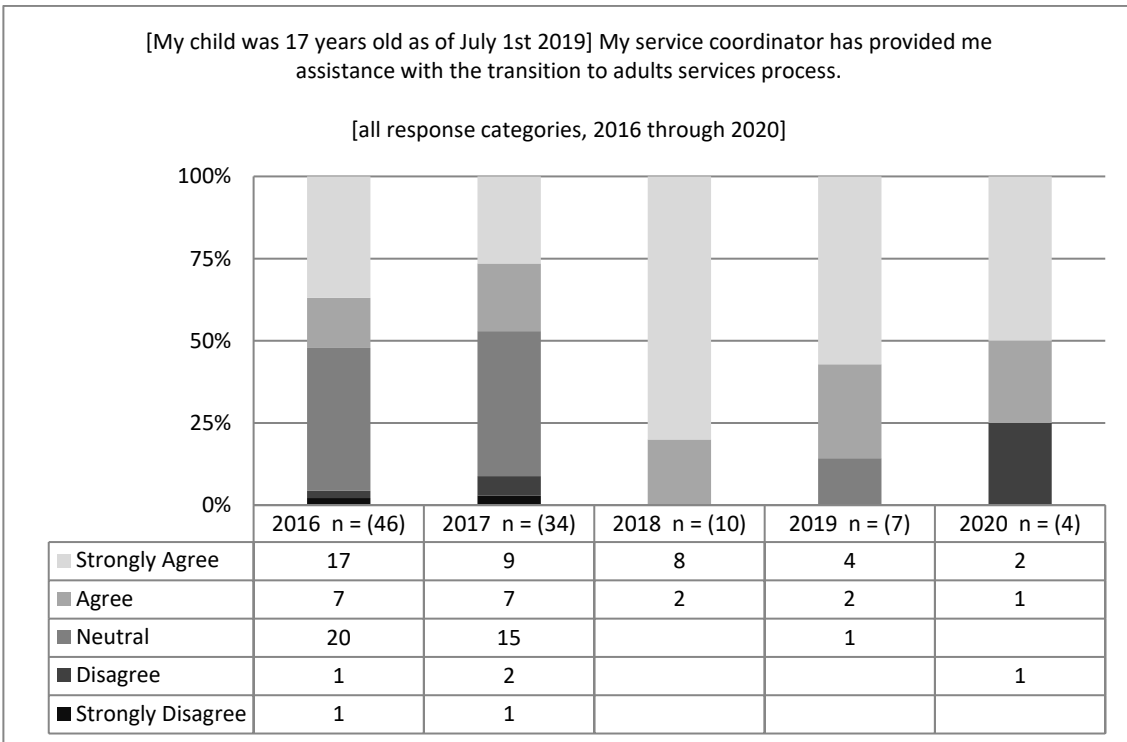


Figure 8b



Question nine asked respondents to state their level of agreement with this statement: *“The goals during this year that my family established as most important were reached through involvement with these programs.”*

Figure 9a shows that the average response (3.9) is closest to “agree,” and that responses to this item have become more positive for the 2nd year in a row. Statistical testing indicates that there is a 94% probability that the increase observed between 2018 and 2020 would still be seen if we would have been able to collect data from every member of the population under study over the past two years.⁶ Figure 9b shows that this change in the average response over the two-year span is driven by a continuing decrease in the proportion of respondents saying they “disagree” or “strongly disagree”.

Figure 9a

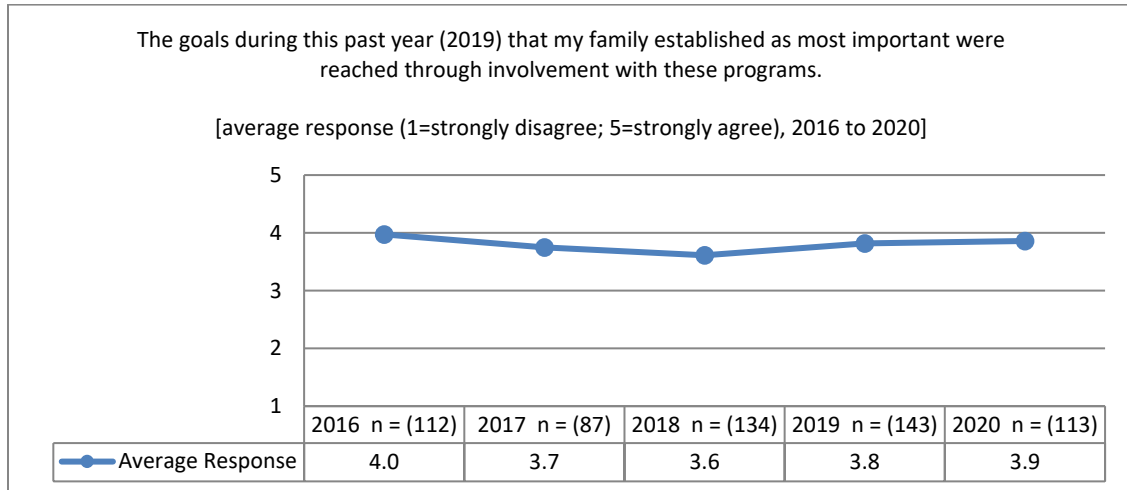
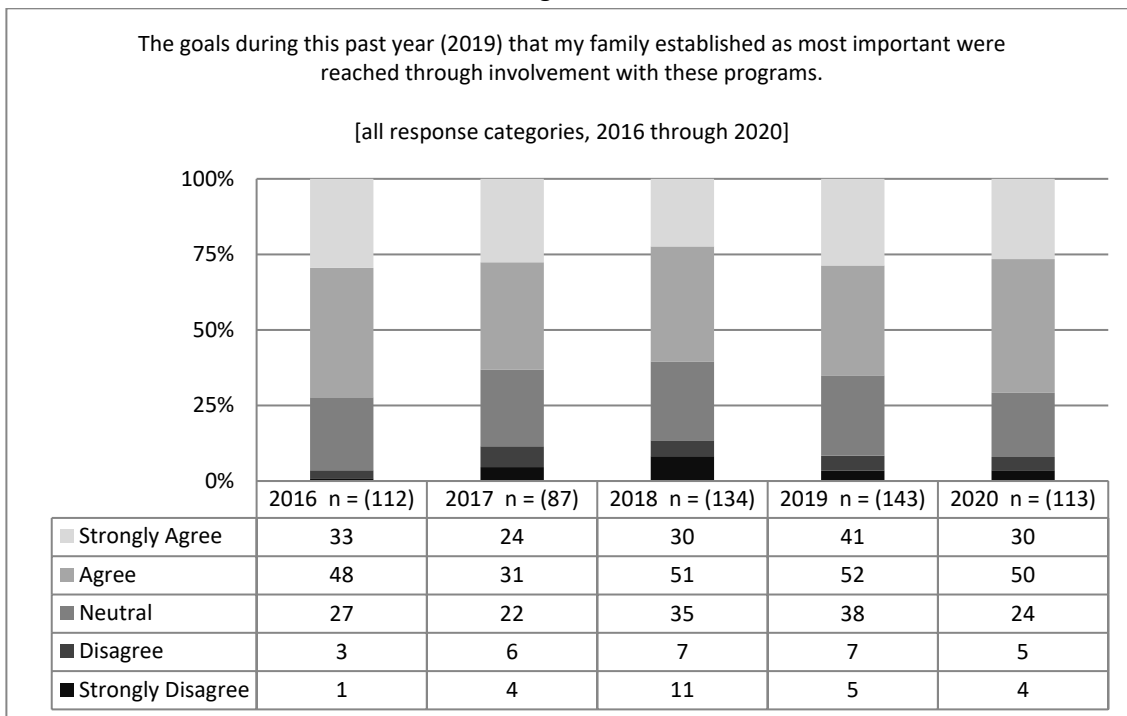


Figure 9b



⁶ $t = 1.80, df = 245, Pr(T < t) = 0.04$

Question ten asked respondents to state agreement or disagreement with the following statement: *“[My child was 17 years old as of July 1st 2019] I feel that as a family we are prepared for the transition to adult services.”*

Figure 10a shows that the average response (3.7) is closest to “agree”, and that the average response has decreased since 2019. However, given the small number of responses to this item over the past three years and the fluctuations in both directions over that timespan, it is likely that these shifts are attributable to sampling error and represent normal variation. Figure 10b shows that one additional respondent answering “disagree” had a sizable impact on the average response.

Similarly to question 8, the eligibility requirement for providing a response to this question was tightened in 2018; whereas in the past respondents with children “close to turning 18” were invited to provide a response, since 2018 respondents are invited to provide a response to this item only if their children were 17 years old as of July 1st of the previous year.

Figure 10a

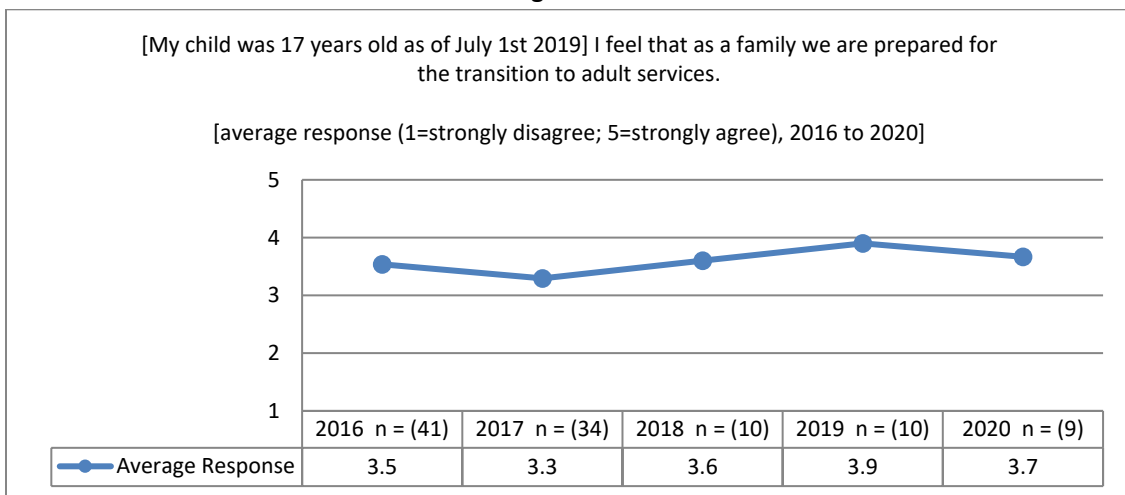
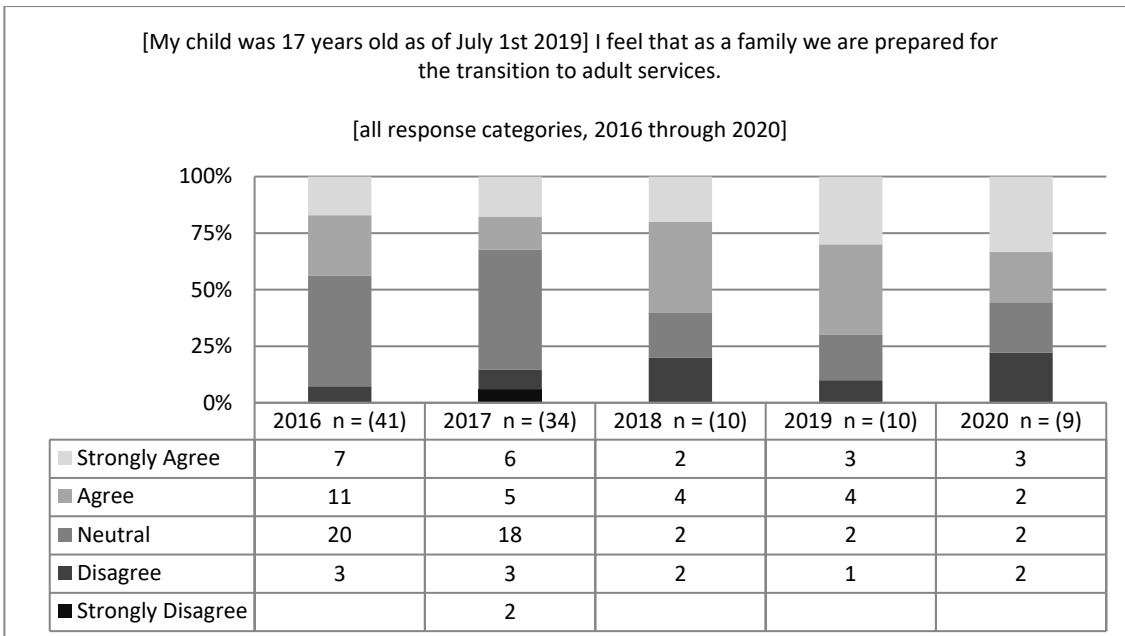


Figure 10b



Question eleven had two parts; the first asked respondents about their level of agreement with the following statement:

“While waiting to receive services, my family and/or child experienced extreme health and safety concern(s).”

Those who answered “agree” or “strongly agree” were asked to state their agreement with a follow-up statement:

“While waiting to receive services, my family was able to address the extreme health and safety concern(s).”

Figure 11a (page 16) shows that the average response to the first question (1.8) is closest to “disagree”, and that disagreement with this statement has, on average, been decreasing incrementally for five straight years. Statistical testing indicates an 88% probability that the observed change between 2019 and 2020 would still be seen had we collected data from every member of the population under study.⁷ Additionally, the size of the overall observed trend between 2016 and 2020 is large enough that there is a nearly 100% probability it would be seen if we had access to complete data from every family during this time period.⁸

Figure 11b (page 16) shows that this trend continues to be driven by increasing proportions of respondents who express certainty that their families/children have not experienced such concerns.

Among those who experienced health and safety concerns while waiting for services, a higher proportion was able to independently address those concerns in 2020 when compared to 2019; in fact, that proportion was at an all-time high in 2020. Figure 11c (page 17) shows that the average response changed from 3.1 (closest to “neutral”) in 2019 to 4.0 (closest to “agree”) in 2020. Despite the small number of observations (16 in 2019, 12 in 2020), statistical testing indicates a 96% probability that this difference would be observed had complete data from the entire population under study been collected.⁹ Figure 11d (page 17) shows a strong shift in the distribution of responses towards strong agreement.

Figure 11e (page 18) shows the complete picture; a smaller proportion of respondents reported emergent health/safety concerns while waiting to receive services in 2020 when compared to 2019, and within the subset of respondents reporting concerns, a lower proportion of this subset said they were unable to address these concerns.

⁷ $t = -1.19$, $df = 244$, $\Pr(T > t) = 0.12$

⁸ $t = -3.13$, $df = 207$, $\Pr(T > t) = 0.00$

⁹ $t = 1.77$, $df = 26$, $\Pr(T > t) = 0.04$

Figure 11a

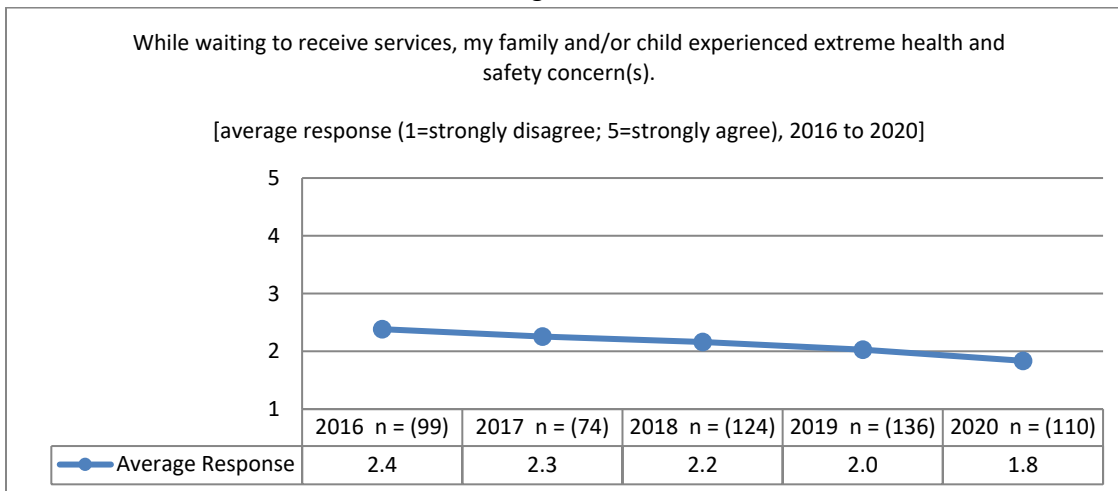


Figure 11b

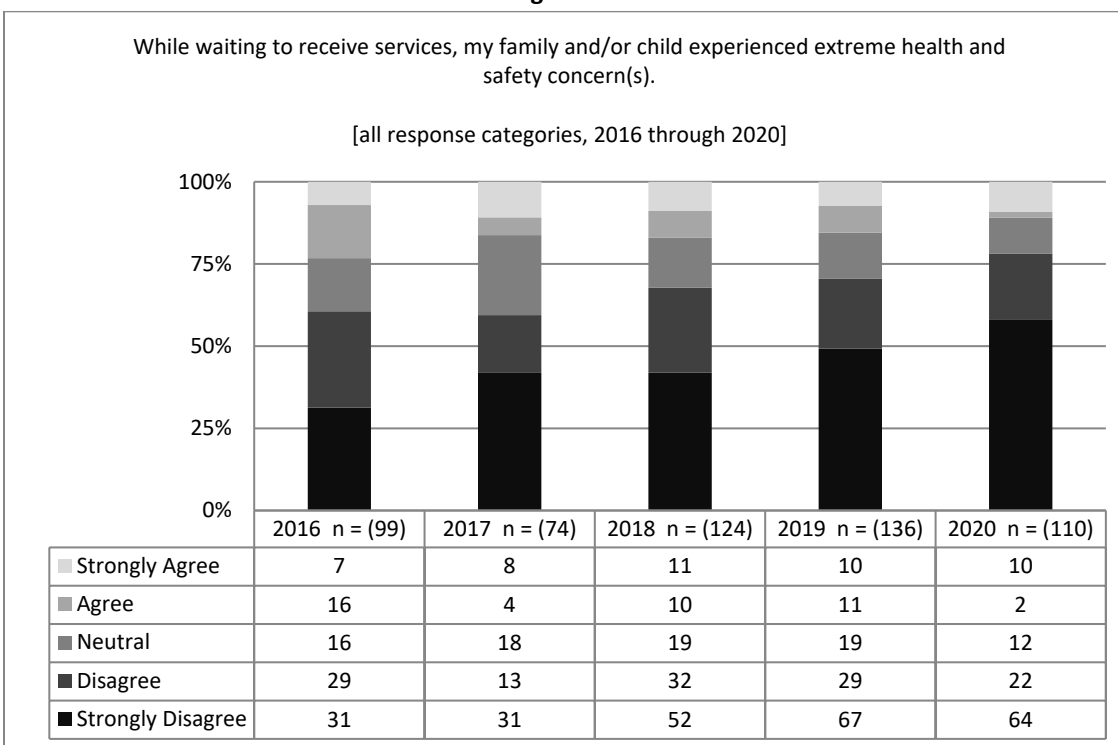


Figure 11c

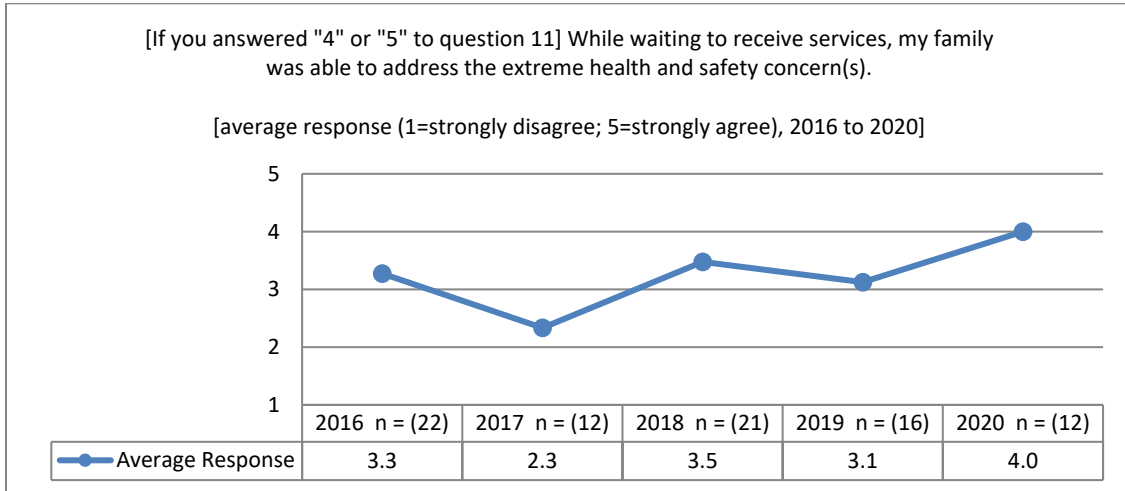


Figure 11d

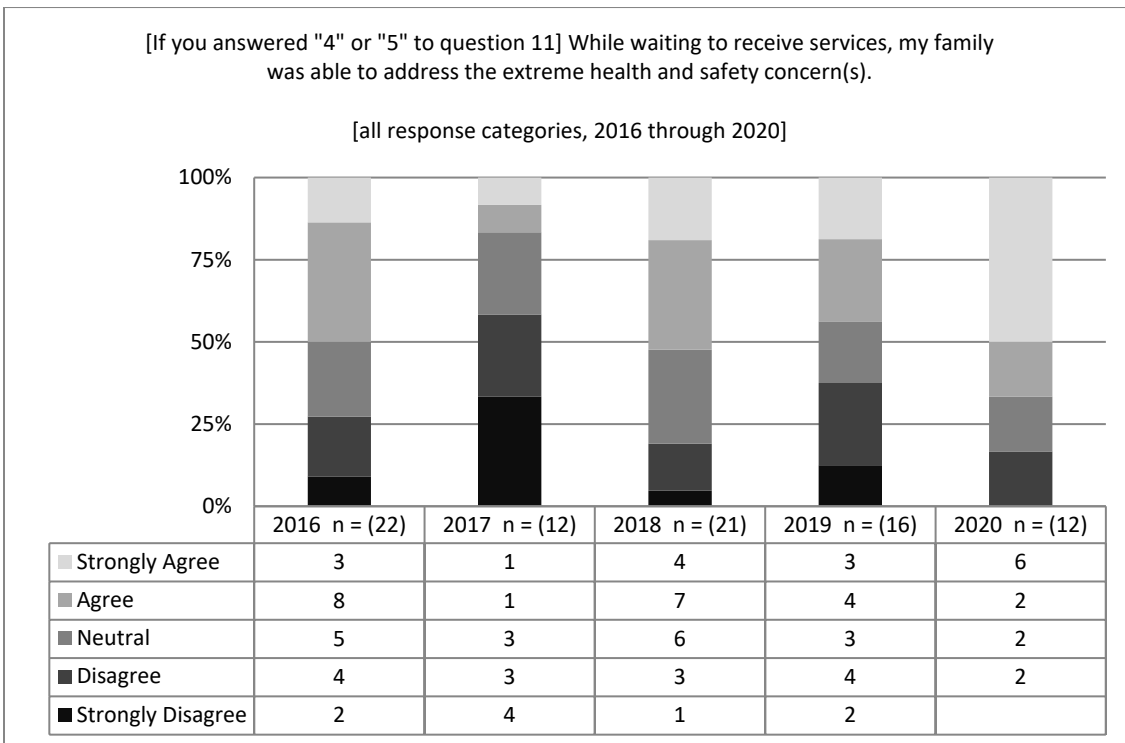
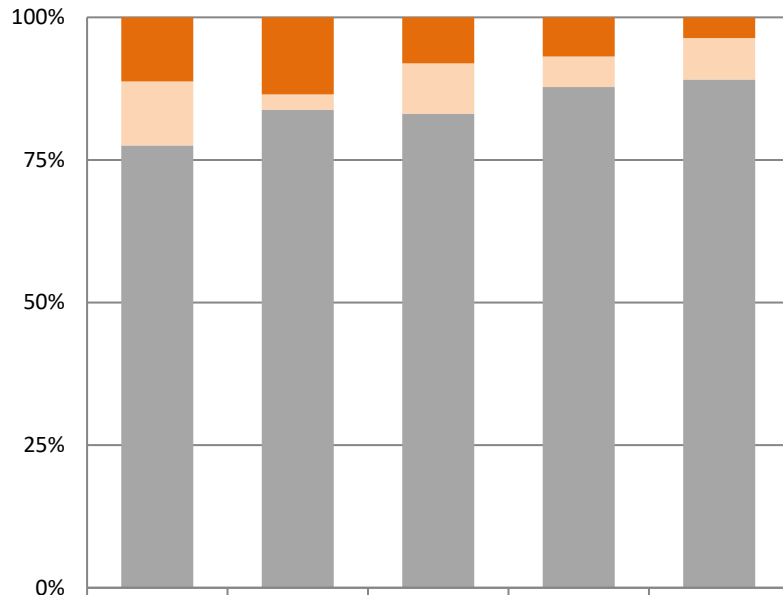


Figure 11e

Net proportion of families that experienced extreme health and/or safety concerns
[2016 through 2020]



	2016	2017	2018	2019	2020
experienced concerns while waiting, were unable to address	11	10	10	9	4
experienced concerns while waiting, were able to address	11	2	11	7	8
did not experience concerns while waiting for services	76	62	103	115	98

Question twelve asked respondents to agree or disagree with the following statement: *“My family’s overall day-to-day functioning improved after we started to receive services through these programs.”* Figure 12a shows that the average response (4.0) is closest to “agree”, and that sentiment regarding this item has now increased incrementally for two years in a row. Statistical testing indicates a 98% probability that the observed increase in the average response to this item over the two-year span would still be apparent were complete data on the entire population under study available.¹⁰ Figure 12b shows the underlying distribution of responses returning to 2017 levels after an overall downward shift in 2018.

Figure 12a

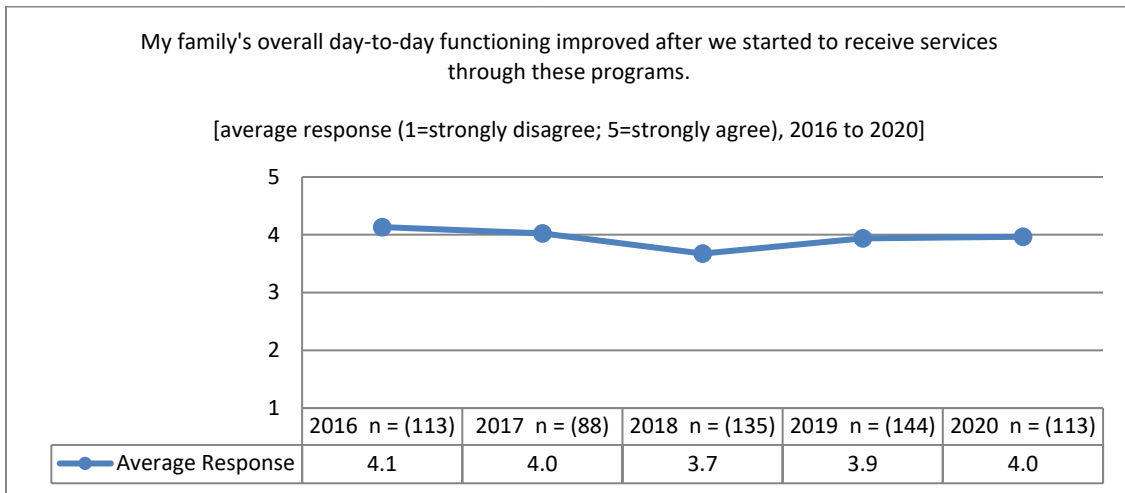
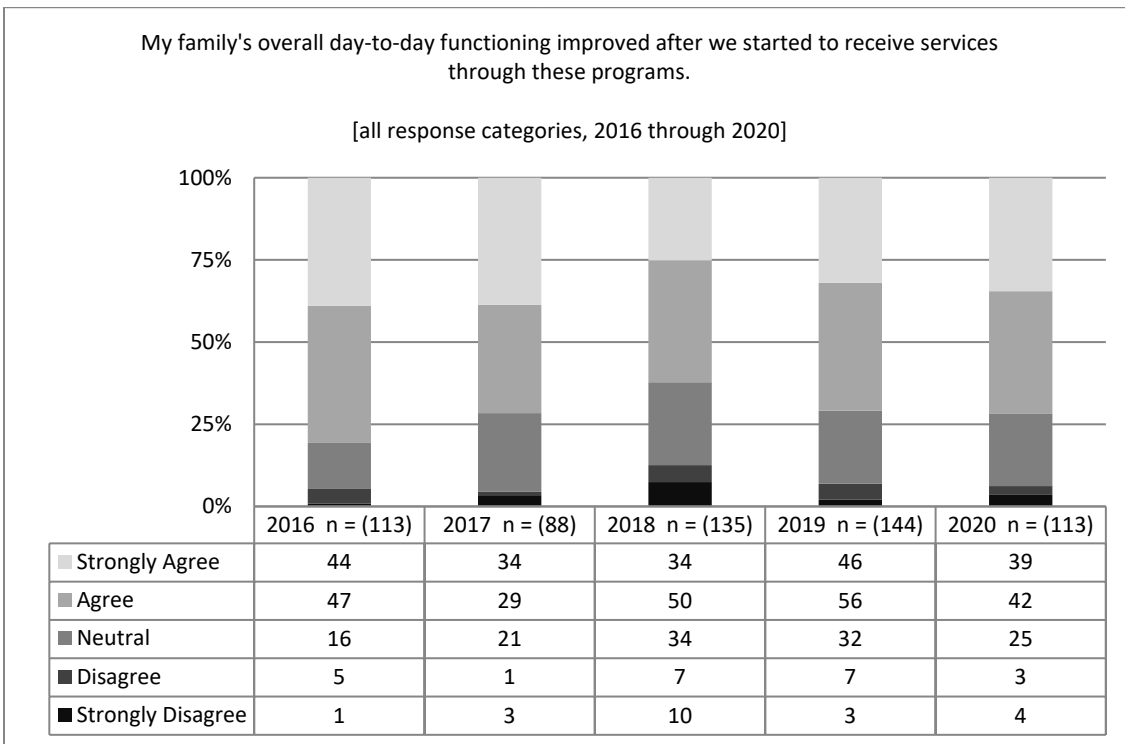


Figure 12b



¹⁰ $t = 2.12$, $df = 246$, $Pr (T < t) = 0.02$

Average Responses by Age Group

This wave, respondents were asked the following question regarding the age of their child:

“Please select the age group that your child was in as of July 1st, 2019: 0 to 5; 6 to 16; 17+”

A total of 113 respondents provided valid answers to this question; the breakdown by age group is shown in Figure 13. The vast majority of respondents (88; 77.9%) reported their child as in the 6-16 age group, while 13 (11.5%) said their child was aged 0-5 and 12 (10.6%) said their child was 17+.

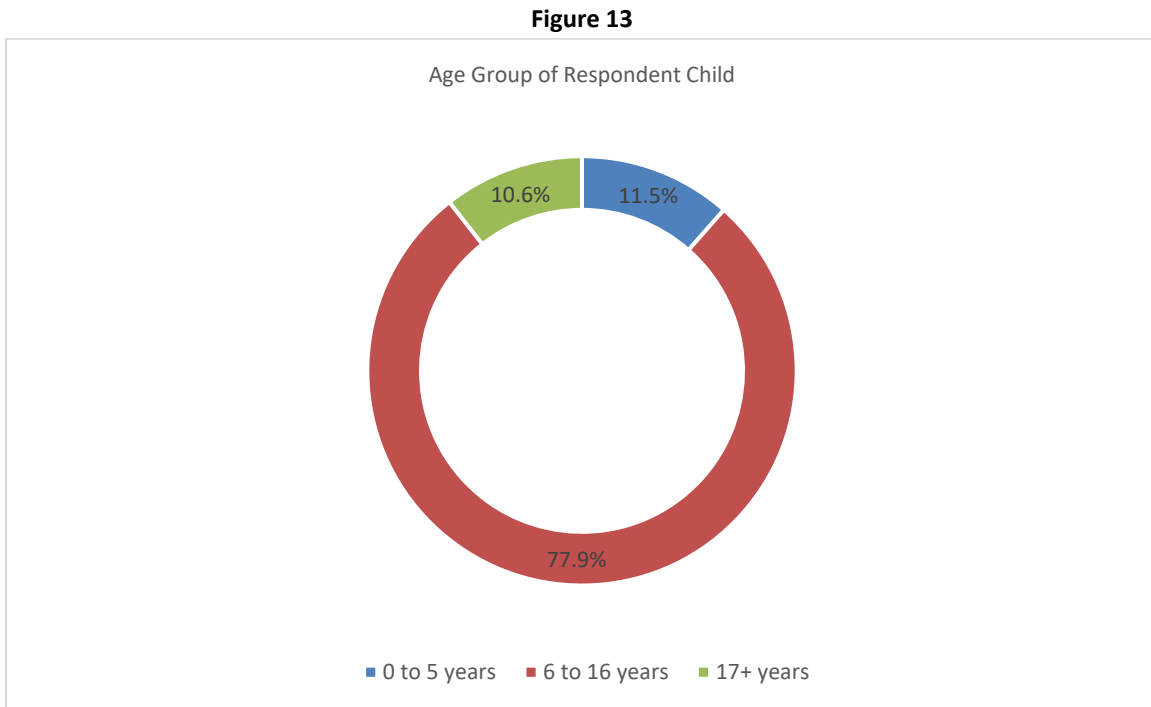
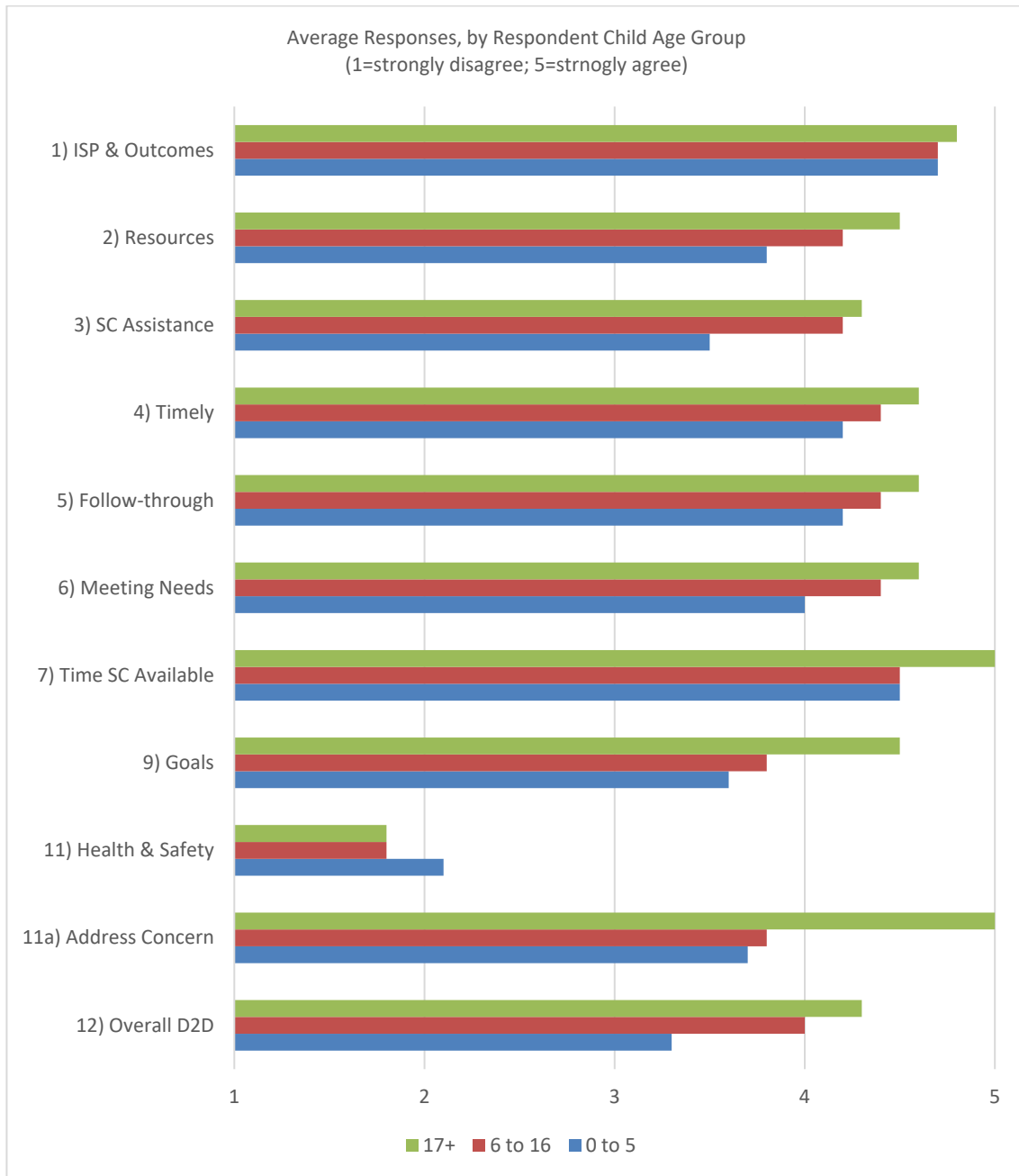


Figure 14 (page 21) breaks down the average response to each question by respondent child age group. Questions 8 and 10 are not represented because every respondent for those questions had a child in the 17+ age group.

Respondents with children aged 17+ had the most favorable average scores for every item (including for Question 11, where disagreement represented a positive result). Respondents with children aged 6 to 16 had responses that were systematically less favorable than those with children aged 17+, but with responses that were more favorable than those with children aged 0 to 5. In some cases (Questions 11 and 12) differences across age groups were large enough to cause the average response to differ by an entire point on the response scale.

Figure 14



Statistical modeling indicates that age range offers meaningful predictive power in terms of respondent opinion when it comes to resources (Question 2), service coordinator assistance (Question 3), goal fulfillment (Question 9), and overall day-to-day functioning (Question 12). Figures 15-18 (pages 22-23) show that in each case, moving from a younger age group to an older age group yields a significant increase in the predicted probability that the respondent volunteers the most positive answer option (5; “strongly agree”).¹¹

¹¹ See Appendix A for complete model parameters.

Figure 15: Change in Predicted Probability of Response Categories Across Respondent Child Age Groups

"I am provided with useful feedback, information, and resources in relation to my child's needs."

(Response outcome scale: 1=strongly disagree; 5=strongly agree)

Age groups: 1 = 0 to 5 years; 2 = 6 to 16 years; 3 = 17+ years)

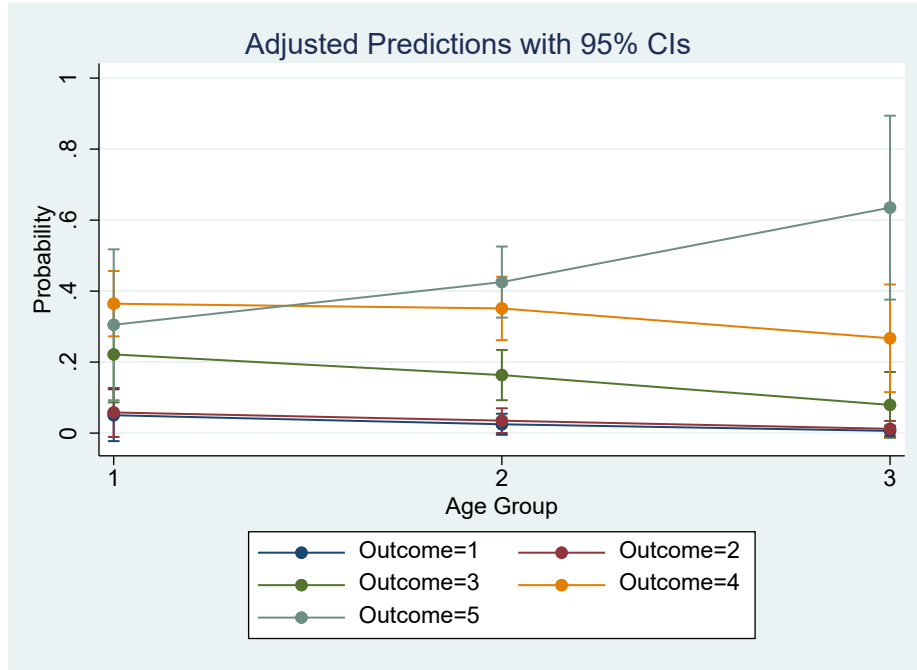


Figure 16: Change in Predicted Probability of Response Categories Across Respondent Child Age Groups

"My service coordinator helps me to better understand the abilities and limitations for the programs that we are currently participating."

(Response outcome scale: 1=strongly disagree; 5=strongly agree)

Age groups: 1 = 0 to 5 years; 2 = 6 to 16 years; 3 = 17+ years)

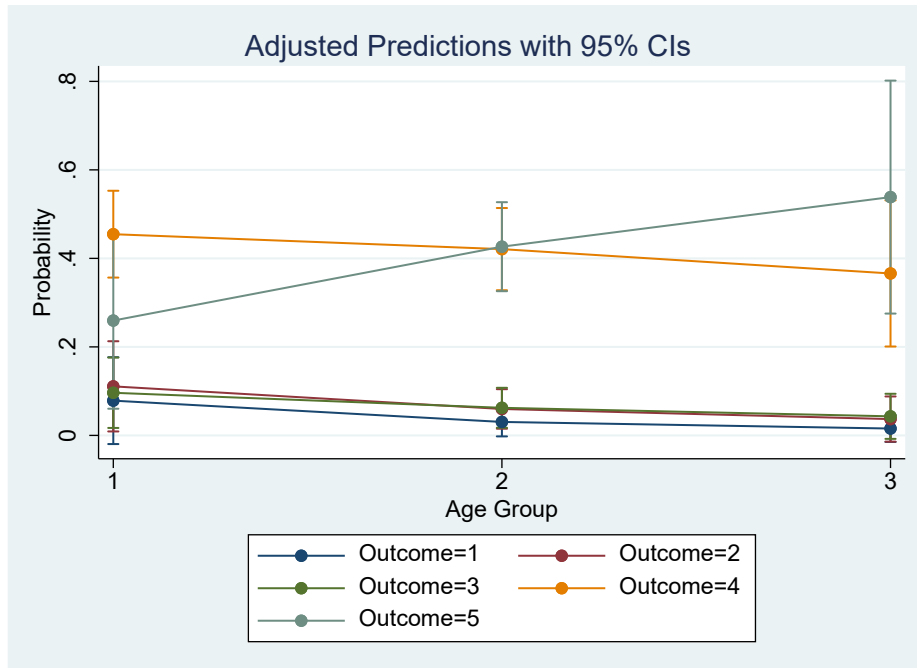


Figure 17: Change in Predicted Probability of Response Categories Across Respondent Child Age Groups
“The goals during this past year (2019) that my family established as most important were reached through involvement with these programs.”

(Response outcome scale: 1=strongly disagree; 5=strongly agree)
 Age groups: 1 = 0 to 5 years; 2 = 6 to 16 years; 3 = 17+ years)

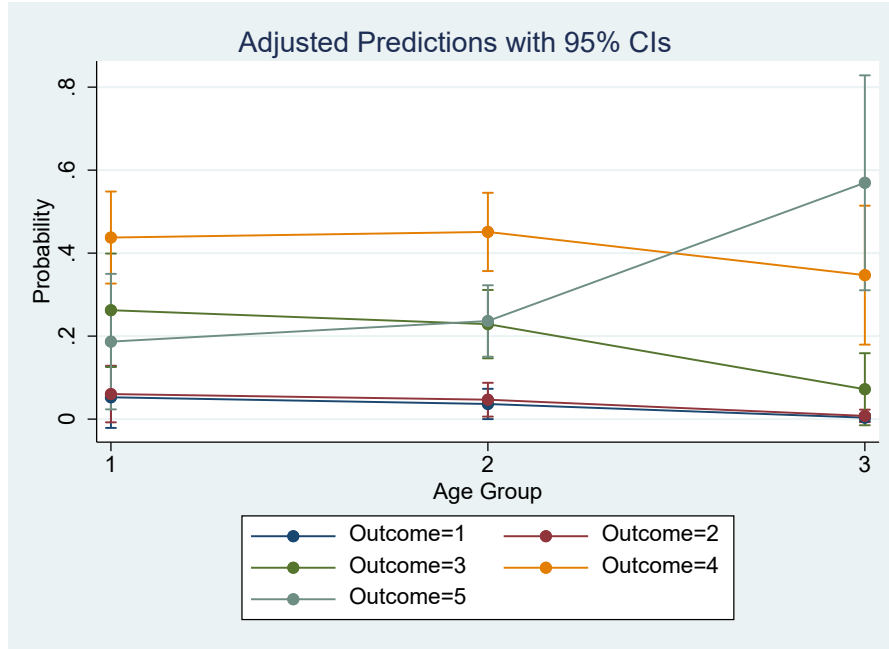
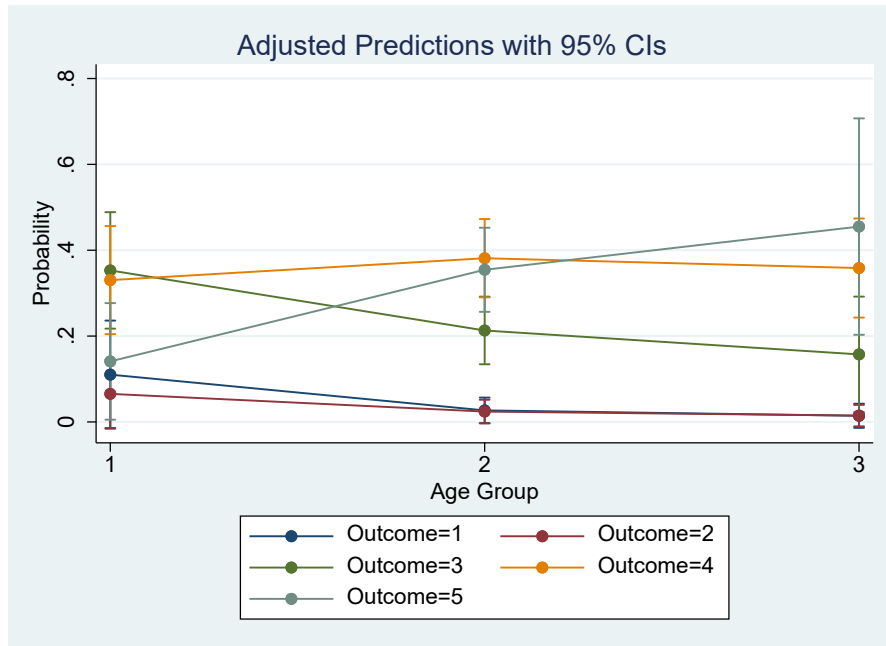


Figure 18: Change in Predicted Probability of Response Categories Across Respondent Child Age Groups
“My family’s overall day-to-day functioning improved after we started to receive services through these programs.”

(Response outcome scale: 1=strongly disagree; 5=strongly agree)
 Age groups: 1 = 0 to 5 years; 2 = 6 to 16 years; 3 = 17+ years)



External Programs and Outside Services

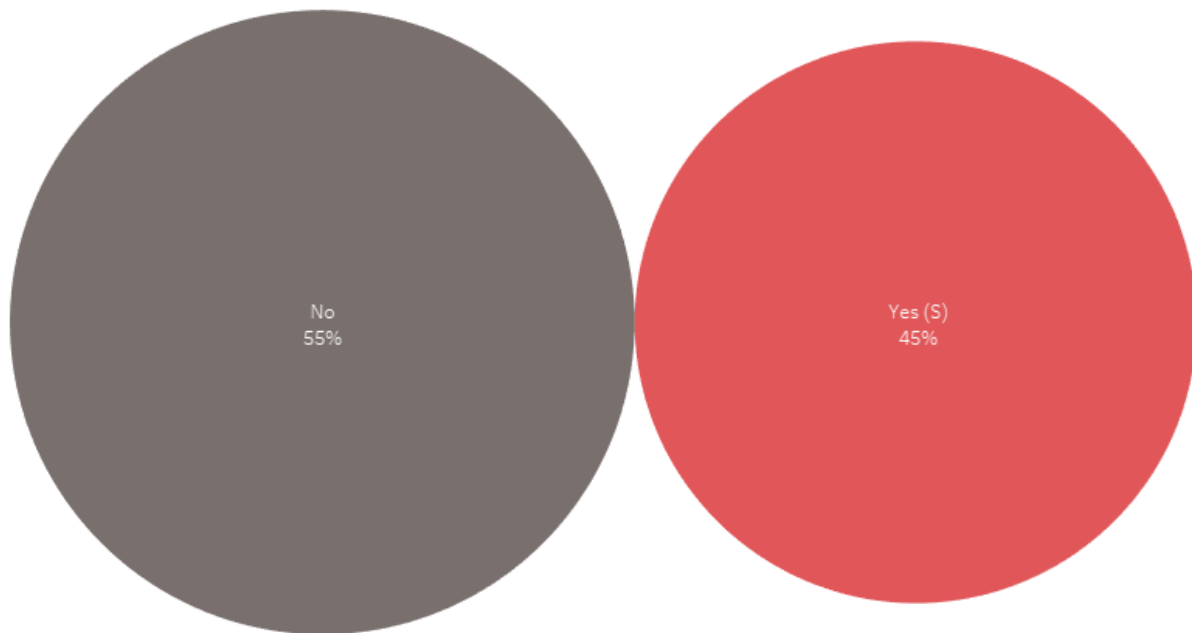
This wave, respondents were asked to indicate whether they had received any of a variety of services related to their child's disability OUTSIDE of those provided by the CSN programs:

- Additional school services
- Formal in-home provider (such as a therapist or specialized medical doctor typically covered through insurance)
- Informal in-home provider (family participates in a service related to the child's disability that is free or privately paid for)
- Formal community provider (such as a therapist or specialized medical doctor typically covered through insurance)
- Informal community provider (family participates in a service related to the child's disability that is free or privately paid for)
- Parent support group

In order to put additional context around respondent opinion regarding service coordinator performance and the efficacy of the CSN programs, multivariate modeling was used to determine the extent to which each of these outside service/program groups were independently related to or associated with responses to each survey question, while controlling for participation in the other external programs/services as well as for the age of the child.¹²

First, respondents were asked about **additional school services**. Figure 18 shows that 45% said they received additional school services in 2020, while 55% did not.

Figure 18: % of Respondents Who Received Additional School Services in 2020



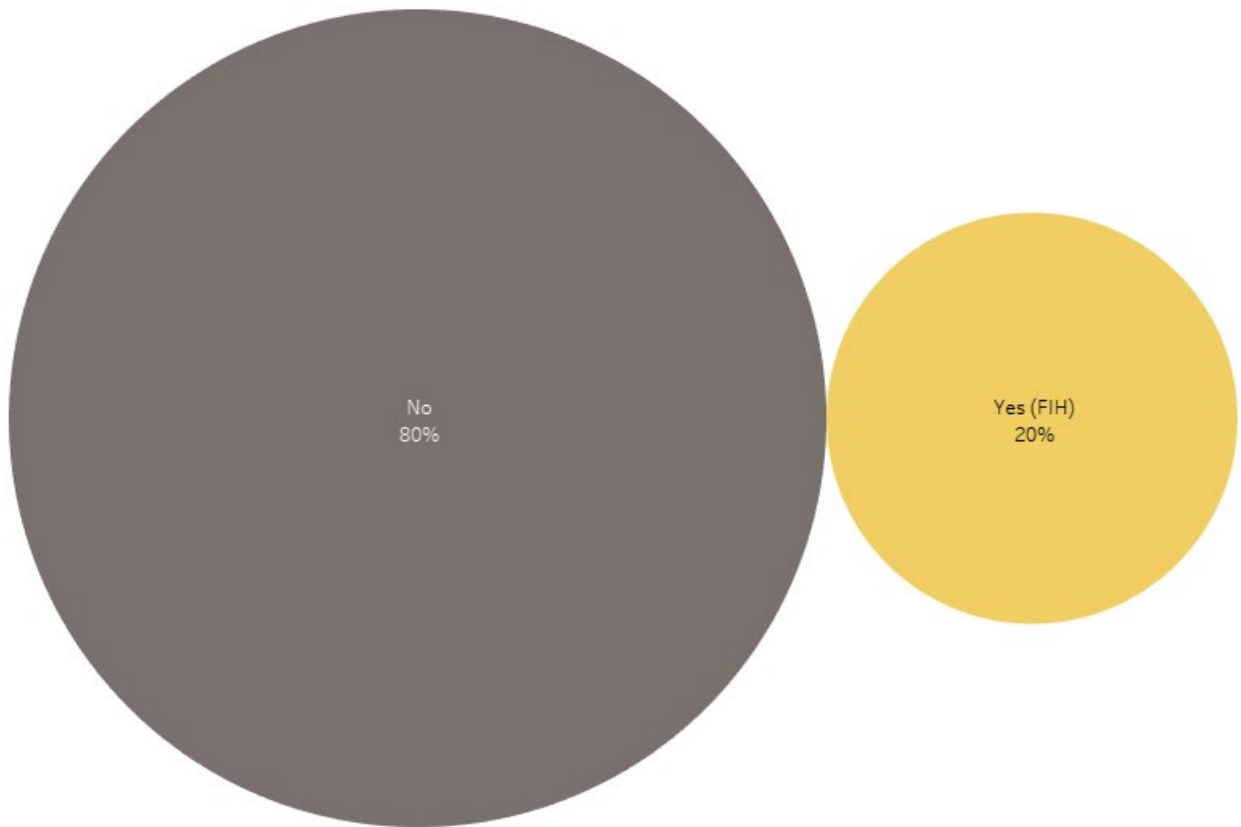
¹² See Appendix B for complete model parameters.

Multivariate modeling indicates that after controlling for other external service provision and child age, receiving additional school services in 2020 was associated with the following survey response patterns:

- Reducing the predicted probability that a respondent “strongly agrees” with the statement “I am involved in the development of my child’s Service Plan and Outcomes” from 76% to 33%.

Second, respondents were asked about **formal in-home providers**. Figure 19 shows that 20% said they received services from formal in-home providers in 2020, while 80% did not.

Figure 19: % of Respondents Who Received Services from Formal In-home Providers in 2020

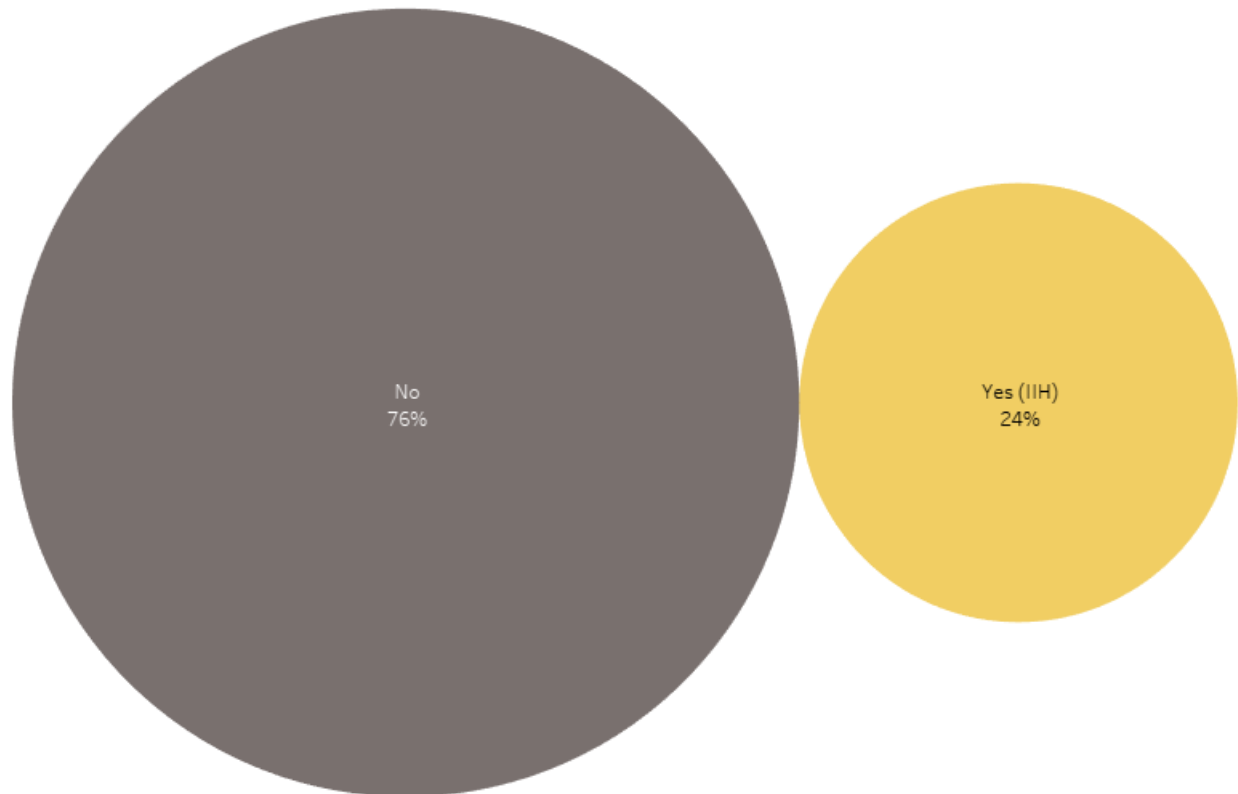


Multivariate modeling indicates that after controlling for other external service provision and child age, receiving services from formal in-home providers in 2020 was associated with the following survey response patterns:

- Reducing the predicted probability that a respondent “strongly agrees” with the statement “My family’s overall day-to-day functioning improved after we started to receive services through these programs” from 34% to 12%.

Third, respondents were asked about **informal in-home providers**. Figure 20 shows that 24% said they received services from informal in-home providers in 2020, while 76% did not.

Figure 20: % of Respondents Who Received Services from Informal In-home Providers in 2020

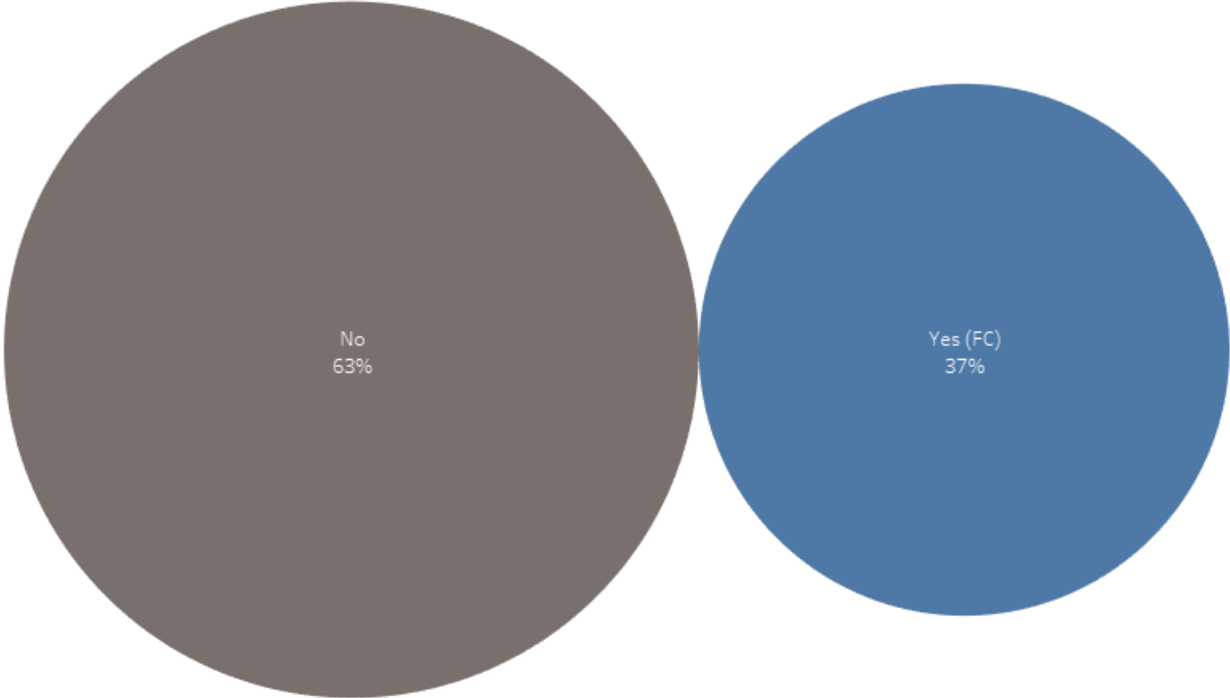


Multivariate modeling indicates that after controlling for other external service provision and child age, receiving services from informal in-home providers in 2020 was associated with the following survey response patterns:

- Increasing the predicted probability that a respondent “strongly agrees” with the statement “My service coordinator assists in meeting the needs of my child and family” from 38% to 55%.
- Increasing the predicted probability that a respondent “strongly agrees” with the statement “I am satisfied with the amount of time my service coordinator is available to my family” from 54% to 73%.

Fourth, respondents were asked about **formal community providers**. Figure 21 shows that 37% said they received services from formal community providers in 2020, while 63% did not.

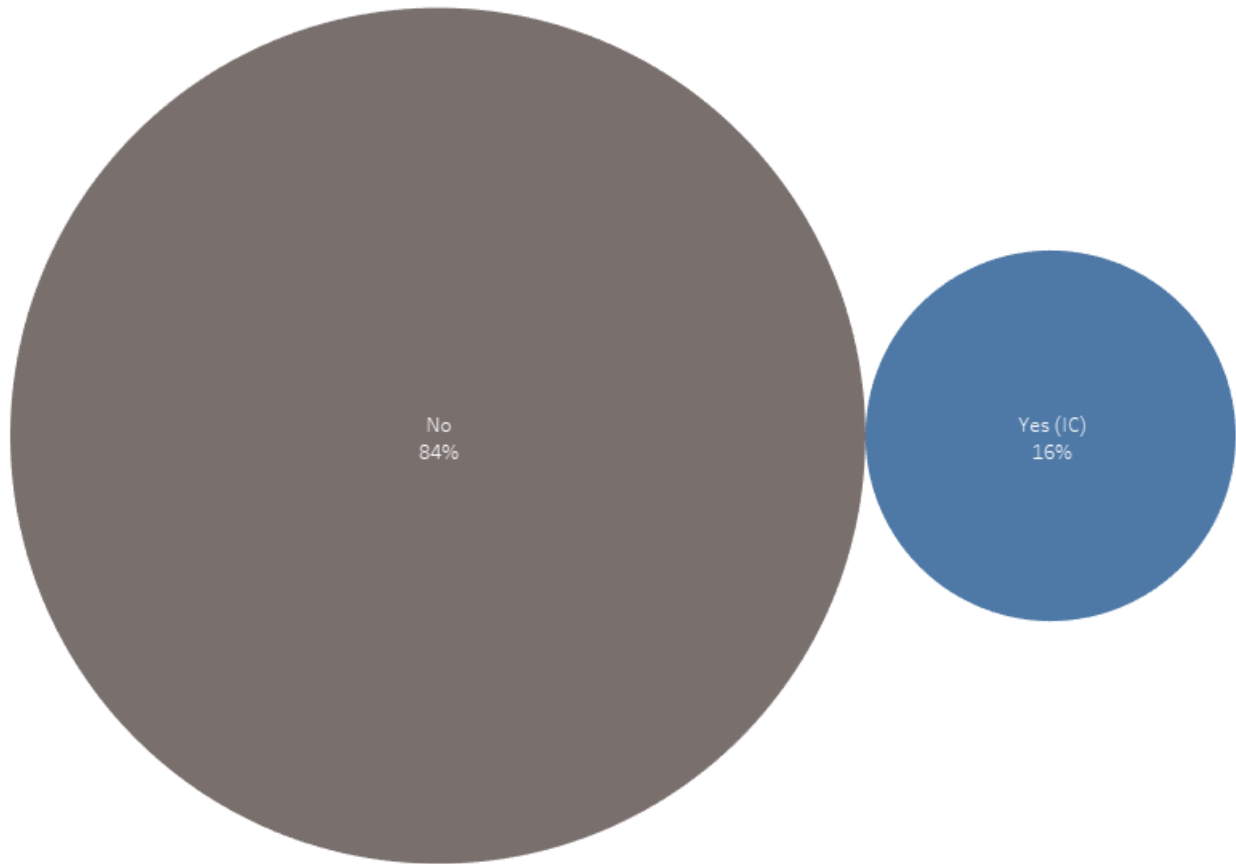
Figure 21: % of Respondents Who Received Services from Formal Community Providers in 2020



Multivariate modeling did not reveal any notable changes in survey response patterns independently associated with receiving service from formal community providers in 2020.

Fifth, respondents were asked about **informal community providers**. Figure 22 shows that 16% said they received services from informal community providers in 2020, while 84% did not.

Figure 22: % of Respondents Who Received Services from Informal Community Providers in 2020

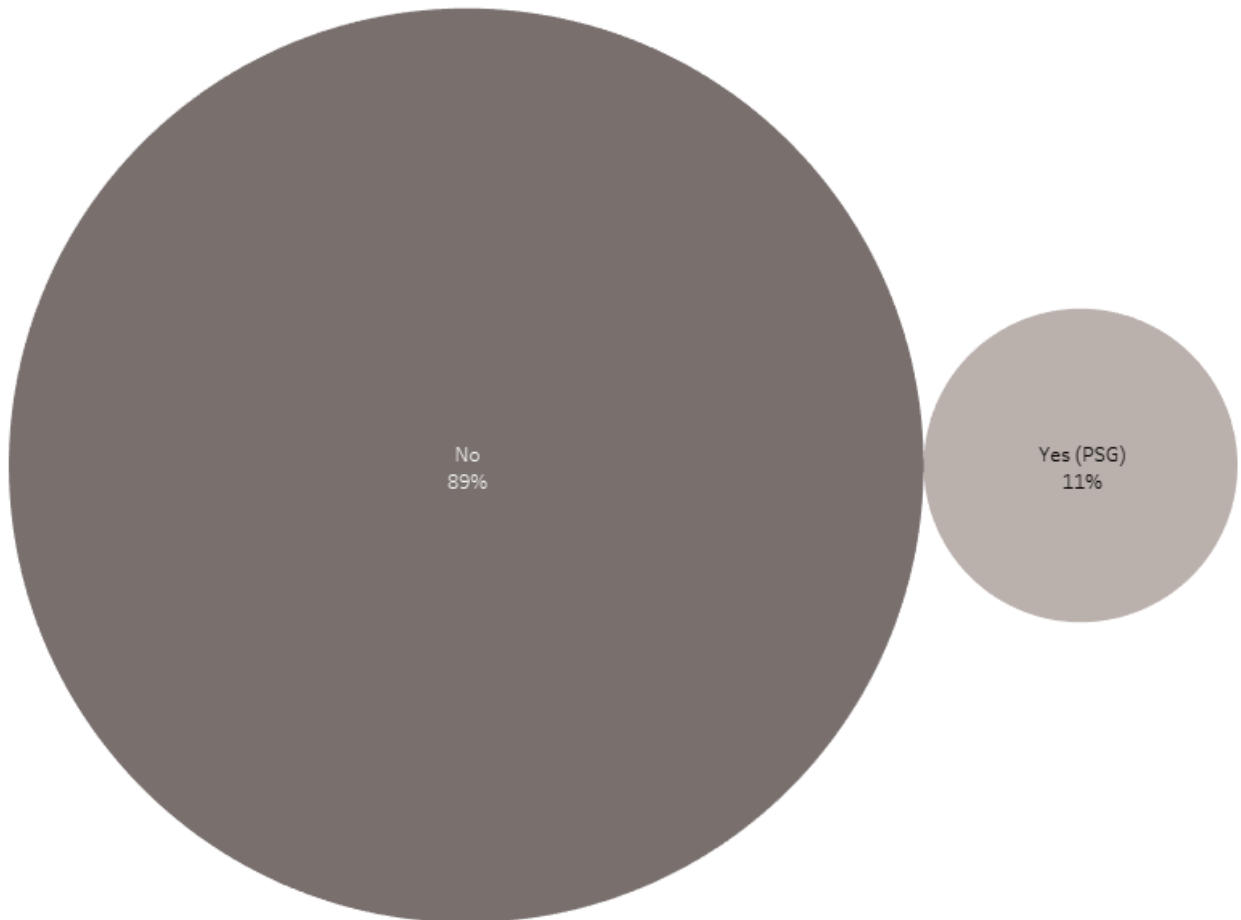


Multivariate modeling indicates that after controlling for other external service provision and child age, receiving services from informal community providers in 2020 was associated with the following survey response patterns:

- Increasing the predicted probability that a respondent “strongly agrees” with the statement “I am provided with useful feedback, information, and resources in relation to my child’s needs” from 39% to 66%.
- Increasing the predicted probability that a respondent “strongly agrees” with the statement “The goals during this past year (2020) that my family established as most important were reached through involvement with these programs” from 24% to 41%.

Sixth, respondents were asked about **parent support groups**. Figure 23 shows that 11% said they participated in parent support groups in 2020, while 89% did not.

Figure 23: % of Respondents Who Received Services from Informal Community Providers in 2020



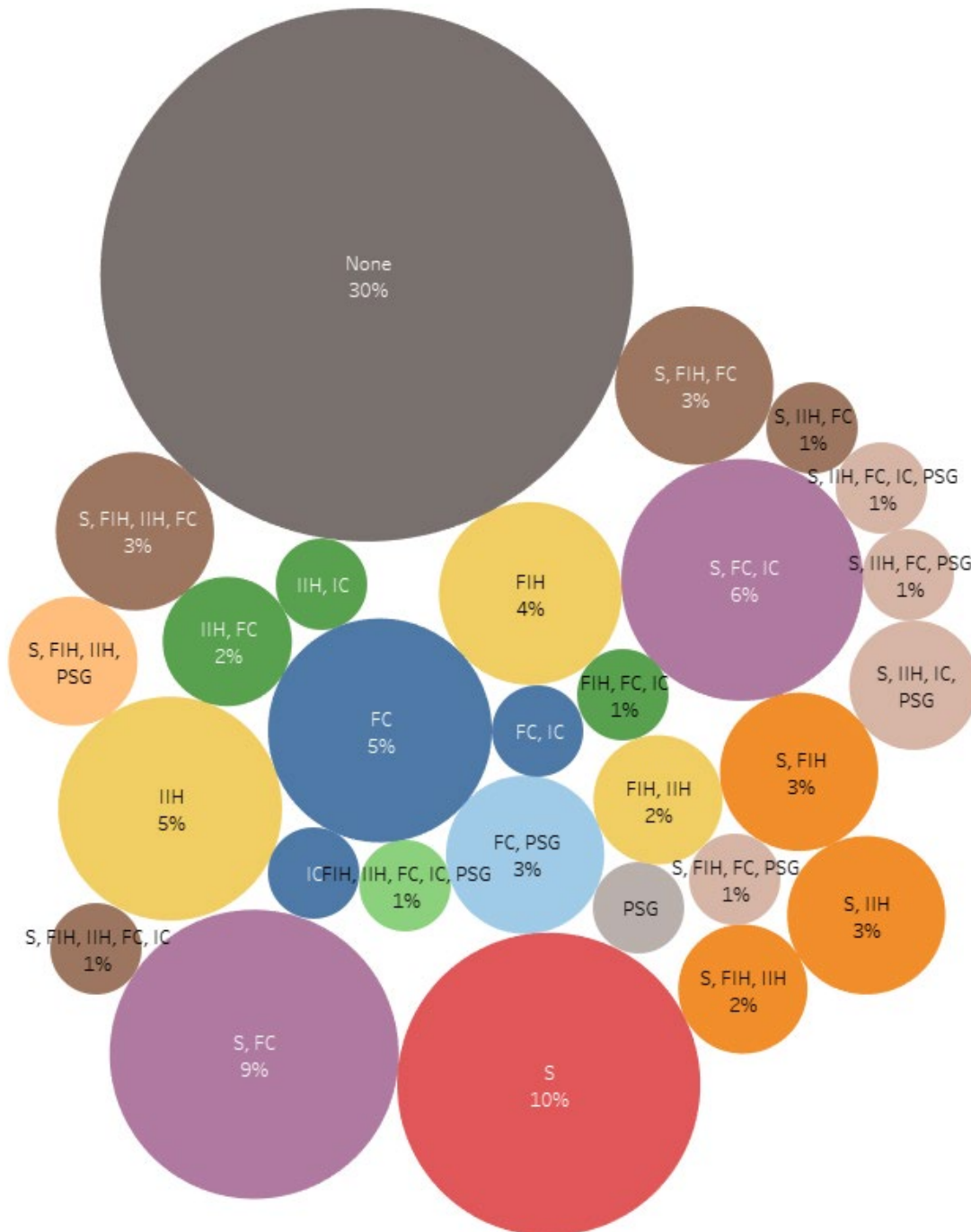
Multivariate modeling indicates that after controlling for other external service provision and child age, receiving services from informal community providers in 2020 was associated with the following survey response patterns:

- Reducing the predicted probability that a respondent “strongly agrees” with the statement “My service coordinator assists in meeting the needs of my child and family” from 59% to 35%.
- Increasing the predicted probability that a respondent “strongly agrees” with the statement “My family’s overall day-to-day functioning improved after we started to receive services through these programs” from 31% to 57%.

Notably, there were negative associations between participation in parent support groups in 2020 and sentiment regarding almost every dimension of service coordinator performance. While these observed negative associations fell short of traditional thresholds for statistical significance, the models indicated that there is an 80-90% probability that such negative associations would be seen had every member of the population of interest been surveyed.

Many respondents indicated that they received services from multiple outside sources in 2020. Figure 24 shows the landscape of outside service participation. School services are colored red; in-home services are colored yellow; community services are colored blue; parent support groups are colored light grey. Combinations of services are colored according to the constituent services described within. The largest group of respondents (30%) reported receiving no external services in 2020; 10% reported receiving additional school services only; 9% reported receiving additional school services and services from formal community providers.

Figure 24: % of Respondents Receiving Various Combinations of Outside Services in 2020



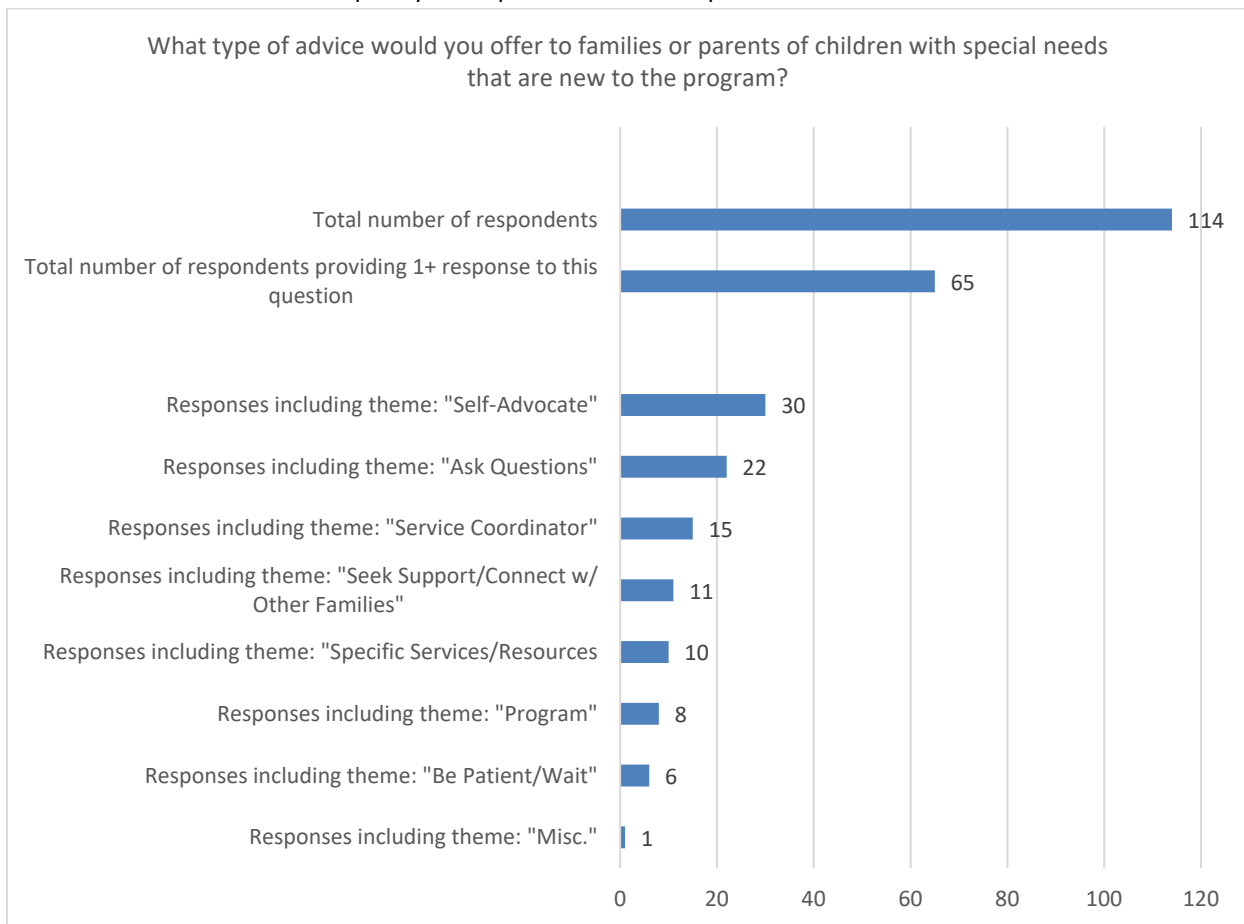
Open-ended Responses

Respondents were also asked a series of open-ended questions. The **first** was as follows:

“What type of advice would you offer to families or parents of children with special needs that are new to the program?”

Out of 114 survey respondents, 65 respondents replied to this question; some respondents provided multiple responses. For analysis purposes, similar responses were grouped into themes (for a complete digest of responses organized by theme, refer to Appendix C). Figure 25 displays the relative frequency of response themes for this question; the most frequently-mentioned themes were “Self-Advocate” (30 mentions), “Ask Questions” (22 mentions), and “Service Coordinator” (15 mentions).

Figure 25
Frequency of Response Themes to Open-Ended Question 1

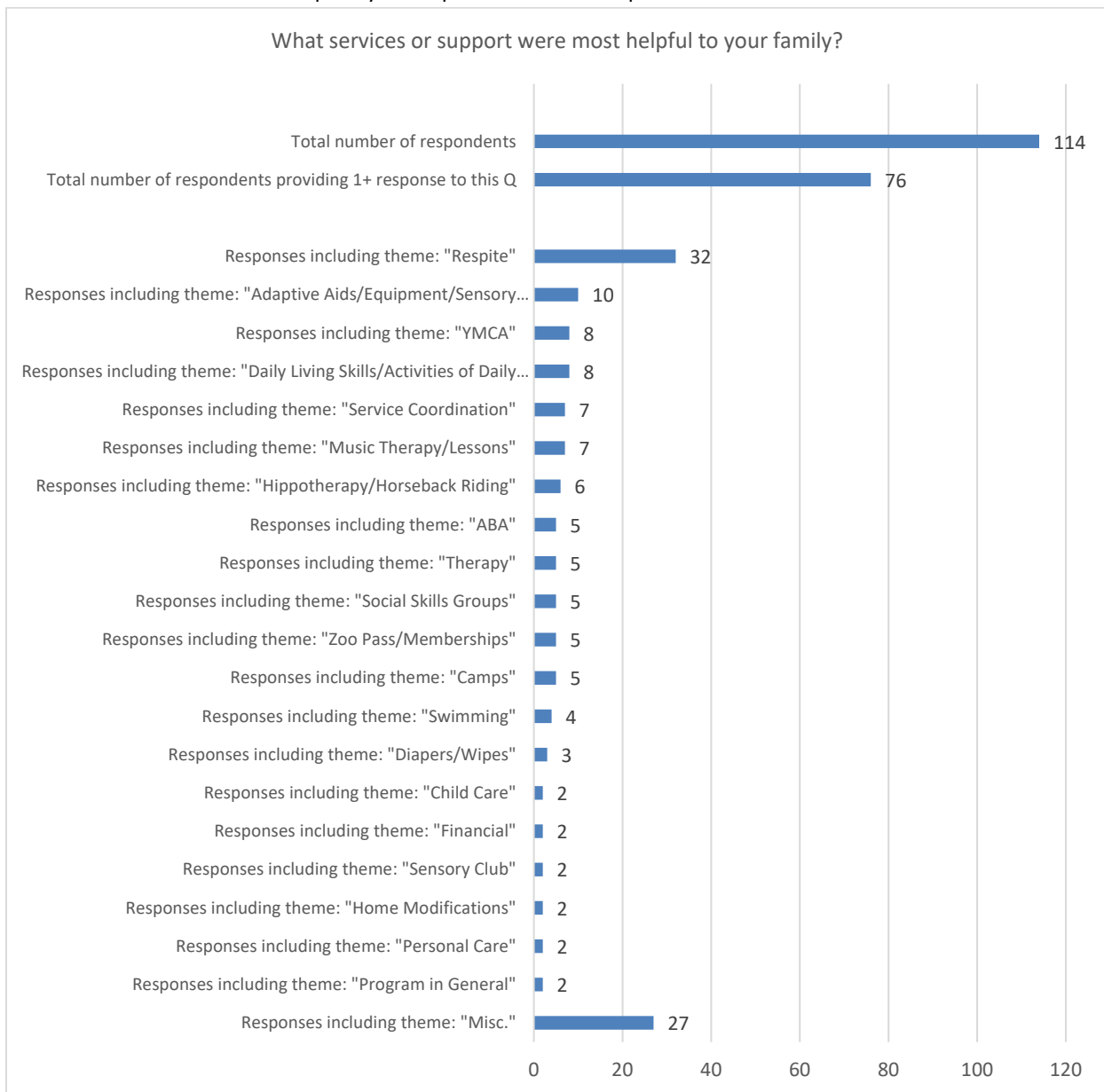


The **second** open-ended question was as follows:

“What services or support were most helpful to your family?”

Out of 114 survey respondents, 105 respondents replied to this question; some respondents provided multiple responses. For analysis purposes, similar responses were grouped into themes (for a complete digest of responses organized by theme, refer to Appendix D). Figure 26 displays the relative frequency of response themes for this question; the most frequently-mentioned themes were “Respite” (32 mentions), “Adaptive Aids/Equipment/Sensory Items” (10 mentions), “YMCA” (8 mentions), and “Daily Living Skills/Activities of Daily Life” (8 mentions).

Figure 26
Frequency of Response Themes to Open-Ended Question 2



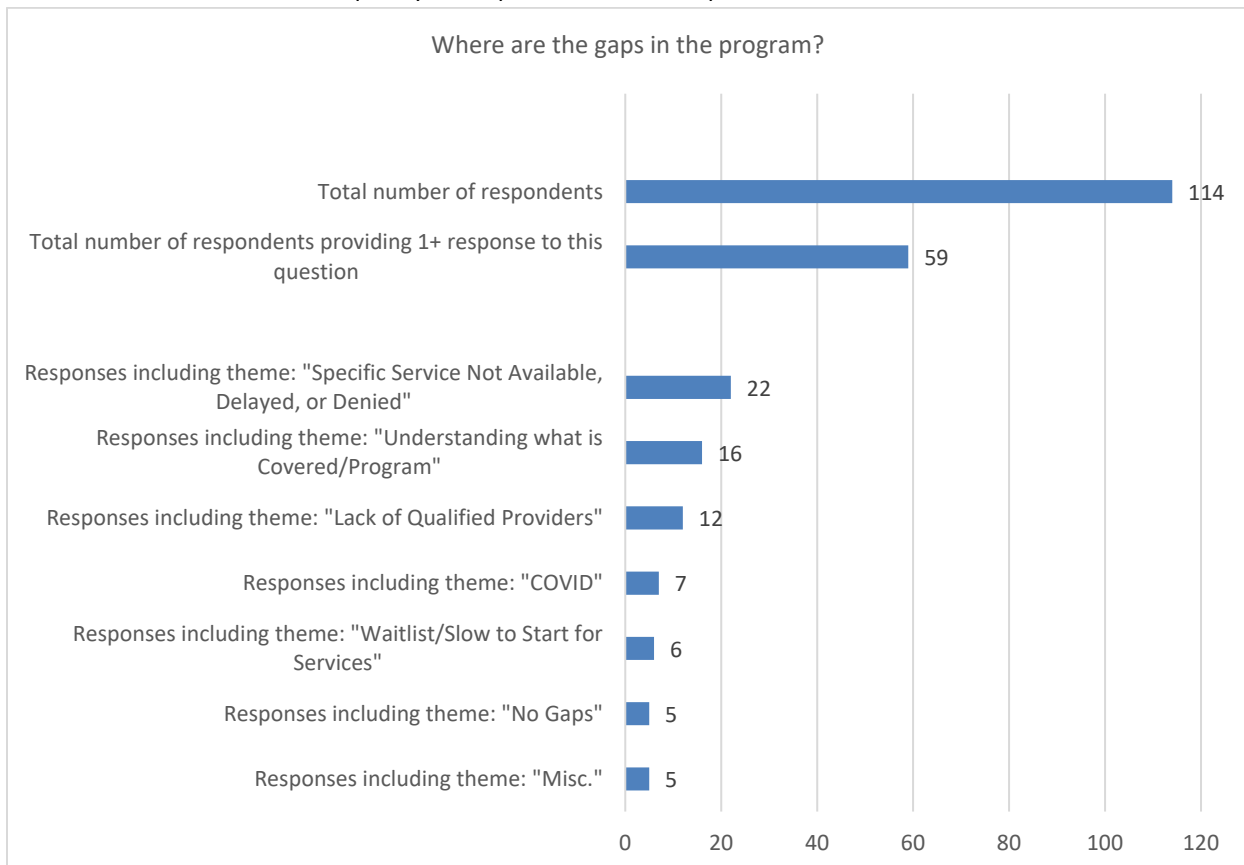
The **third** open-ended question was as follows:

“Where are the gaps in services/support?”

Out of 114 survey respondents, 59 respondents replied to this question; some respondents provided multiple responses. For analysis purposes, similar responses were grouped into themes (for a complete digest of responses organized by theme, refer to Appendix E). Figure 27 displays the relative frequency of response themes for this question; the most frequently-mentioned themes were “Specific Service Not Available, Delayed, or Denied” (22 mentions), “Understanding what is Covered/Program” (17 mentions), and “Lack of Qualified Providers” (12 mentions).

Figure 18 shows a breakdown of sub-themes within the “Specific Service Not Available, Delayed, or Denied” theme; of the 29 mentions in that theme, “Respite” (6 mentions) and “Therapy/Mental Health” (4 mentions) were the most common sub-themes.

Figure 27
Frequency of Response Themes to Open-Ended Question 3



Appendix A

Model Parameters for Figures 15-18 (pages 22-23)

(Ordered Probit)

Parameters generated using Stata/SE 15.1

```
. oprobit goals i.agegroup
```

```
Iteration 0:  log likelihood = -145.8711
Iteration 1:  log likelihood = -142.31826
Iteration 2:  log likelihood = -142.31078
Iteration 3:  log likelihood = -142.31078
```

```
Ordered probit regression              Number of obs   =       112
                                      LR chi2(2)       =        7.12
                                      Prob > chi2      =       0.0284
Log likelihood = -142.31078           Pseudo R2      =       0.0244
```

goals	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]	

agegroup						
2	.1721875	.3174715	0.54	0.588	-.4500453	.7944203
3	1.065055	.4520229	2.36	0.018	.1791059	1.951003

/cut1	-1.619801	.3501939			-2.306168	-.9334336
/cut2	-1.210132	.3229691			-1.84314	-.5771243
/cut3	-.3169491	.3051812			-.9150932	.281195
/cut4	.8898553	.310203			.2818685	1.497842

```
. oprobit overalld2d i.agegroup
```

```
Iteration 0:  log likelihood = -143.94857
Iteration 1:  log likelihood = -140.94865
Iteration 2:  log likelihood = -140.94792
Iteration 3:  log likelihood = -140.94792
```

```
Ordered probit regression              Number of obs   =       112
                                      LR chi2(2)       =        6.00
                                      Prob > chi2      =       0.0498
Log likelihood = -140.94792           Pseudo R2      =       0.0208
```

overalld2d	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]	

agegroup						
2	.7024641	.3172435	2.21	0.027	.0806783	1.32425
3	.9630479	.4375732	2.20	0.028	.1054202	1.820676

/cut1	-1.225316	.3410998			-1.893859	-.5567727
/cut2	-.932091	.3224659			-1.564113	-.3000695
/cut3	.0718337	.3013542			-.5188097	.6624771
/cut4	1.075818	.3097031			.4688106	1.682824

```
. oprobit cmassistance i.agegroup
```

```
Iteration 0: log likelihood = -133.77008  
Iteration 1: log likelihood = -132.30308  
Iteration 2: log likelihood = -132.30258  
Iteration 3: log likelihood = -132.30258
```

```
Ordered probit regression                Number of obs   =       112  
                                         LR chi2(2)      =         2.93  
                                         Prob > chi2     =         0.2305  
Log likelihood = -132.30258             Pseudo R2       =         0.0110
```

cmassistance	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]	
-----+-----						
agegroup						
2	.459477	.3259458	1.41	0.159	-.1793649	1.098319
3	.7415962	.4516302	1.64	0.101	-.1435828	1.626775
-----+-----						
/cut1	-1.414798	.3414024			-2.083934	-.7456617
/cut2	-.8800443	.3162463			-1.499876	-.2602129
/cut3	-.5657668	.3148039			-1.182771	.0512376
/cut4	.6448975	.3136494			.0301559	1.259639
-----+-----						

```
. oprobit resources i.agegroup
```

```
Iteration 0: log likelihood = -139.74902  
Iteration 1: log likelihood = -137.98382  
Iteration 2: log likelihood = -137.98102  
Iteration 3: log likelihood = -137.98102
```

```
Ordered probit regression                Number of obs   =       113  
                                         LR chi2(2)      =         3.54  
                                         Prob > chi2     =         0.1707  
Log likelihood = -137.98102             Pseudo R2       =         0.0127
```

resources	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]	
-----+-----						
agegroup						
2	.3216719	.3220206	1.00	0.318	-.3094769	.9528207
3	.8550694	.4617162	1.85	0.064	-.0498778	1.760017
-----+-----						
/cut1	-1.640314	.3587573			-2.343465	-.9371624
/cut2	-1.233722	.3234929			-1.867757	-.5996877
/cut3	-.4390289	.3104103			-1.047422	.1693642
/cut4	.5097562	.3095879			-.0970249	1.116537
-----+-----						

Appendix B

Model Parameters for External Programs and Outside Services (pages 24-29)

(Ordered Logit)

Parameters generated using Stata/SE 15.1

```
Iteration 0: log likelihood = -75.434313
Iteration 1: log likelihood = -72.567036
Iteration 2: log likelihood = -72.501889
Iteration 3: log likelihood = -72.501851
Iteration 4: log likelihood = -72.501851
```

```
Ordered logistic regression      Number of obs   =      112
                                LR chi2(8)       =       5.86
                                Prob > chi2        =      0.6624
Log likelihood = -72.501851     Pseudo R2      =      0.0389
```

ispoutcomes	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]	
additionalsschoolservices	-.8228511	.4973908	-1.65	0.098	-1.797719	.1520169
formalinhomeprovider	-.5662309	.5436158	-1.04	0.298	-1.631698	.4992366
informalinhomeprovider	.5198515	.5916827	0.88	0.380	-.6398253	1.679528
formalcommunityprovider	.6474471	.5204502	1.24	0.213	-.3726165	1.667511
informalcommunityprovider	-.1837938	.64353	-0.29	0.775	-1.445089	1.077502
parentsupportgroup	-.4912221	.7308611	-0.67	0.502	-1.923684	.9412393
agegroup						
2	.0859759	.7347166	0.12	0.907	-1.354042	1.525994
3	-.0712474	.9613633	-0.07	0.941	-1.955485	1.81299
/cut1	-5.001576	1.22198			-7.396612	-2.60654
/cut2	-3.585529	.8642102			-5.27935	-1.891708
/cut3	-1.36998	.7193677			-2.779915	.0399549

```
Iteration 0: log likelihood = -139.74902
Iteration 1: log likelihood = -133.16872
Iteration 2: log likelihood = -133.09236
Iteration 3: log likelihood = -133.09228
Iteration 4: log likelihood = -133.09228
```

```
Ordered logistic regression      Number of obs   =      113
                                LR chi2(8)       =     13.31
                                Prob > chi2        =      0.1015
Log likelihood = -133.09228     Pseudo R2      =      0.0476
```

resources	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]	
additionalsschoolservices	-.0633822	.3896468	-0.16	0.871	-.8270759	.7003116
formalinhomeprovider	-.6785593	.4432677	-1.53	0.126	-1.547348	.1902295
informalinhomeprovider	.6105604	.4521938	1.35	0.177	-.2757233	1.496844
formalcommunityprovider	-.0064393	.3970944	-0.02	0.987	-.7847301	.7718515
informalcommunityprovider	1.156497	.561399	2.06	0.039	.0561751	2.256819
parentsupportgroup	-.8900641	.585319	-1.52	0.128	-2.037268	.2571401
agegroup						
2	.6143138	.6162714	1.00	0.319	-.5935559	1.822183
3	1.671409	.857363	1.95	0.051	-.0089912	3.35181

/cut1	-3.090319	.8023562			-4.662909	-1.51773
/cut2	-2.194348	.6830048			-3.533013	-.8556836
/cut3	-.6794645	.6239798			-1.902442	.5435134
/cut4	.9901811	.620545			-.2260647	2.206427

Iteration 0: log likelihood = -133.77008
Iteration 1: log likelihood = -129.68368
Iteration 2: log likelihood = -129.65625
Iteration 3: log likelihood = -129.65624
Iteration 4: log likelihood = -129.65624

Ordered logistic regression	Number of obs	=	112
	LR chi2(8)	=	8.23
	Prob > chi2	=	0.4116
Log likelihood = -129.65624	Pseudo R2	=	0.0308

cmassistance	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]
additionalschoolservices	-.3267068	.3962049	-0.82	0.410	-1.103254 .4498406
formalinhomeprovider	-.2568863	.4524351	-0.57	0.570	-1.143643 .6298703
informalinhomeprovider	.7391389	.4570389	1.62	0.106	-.1566408 1.634919
formalcommunityprovider	.1236302	.401644	0.31	0.758	-.6635775 .9108379
informalcommunityprovider	.5014324	.5364122	0.93	0.350	-.5499162 1.552781
parentsupportgroup	-.827563	.5850402	-1.41	0.157	-1.974221 .3190948
agegroup					
2	.8663212	.6395779	1.35	0.176	-.3872285 2.119871
3	1.392854	.8511413	1.64	0.102	-.2753526 3.06106
/cut1	-2.596032	.7591706			-4.083979 -1.108085
/cut2	-1.488352	.6684336			-2.798457 -1.1782457
/cut3	-.8966295	.6563484			-2.183049 .3897898
/cut4	1.191187	.653066			-.0887989 2.471173

Iteration 0: log likelihood = -118.47596
Iteration 1: log likelihood = -116.64584
Iteration 2: log likelihood = -116.63451
Iteration 3: log likelihood = -116.6345

Ordered logistic regression	Number of obs	=	112
	LR chi2(8)	=	3.68
	Prob > chi2	=	0.8845
Log likelihood = -116.6345	Pseudo R2	=	0.0155

timely	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]
additionalschoolservices	-.0085531	.4164374	-0.02	0.984	-.8247554 .8076492
formalinhomeprovider	-.3063359	.4697123	-0.65	0.514	-1.226955 .6142833
informalinhomeprovider	.176792	.4676115	0.38	0.705	-.7397098 1.093294
formalcommunityprovider	.0727577	.4228494	0.17	0.863	-.7560119 .9015273
informalcommunityprovider	.4894632	.5816598	0.84	0.400	-.650569 1.629495
parentsupportgroup	-.8486541	.5901184	-1.44	0.150	-2.005265 .3079568
agegroup					
2	.1200693	.6287024	0.19	0.849	-1.112165 1.352303
3	.536715	.8466068	0.63	0.526	-1.122604 2.196034
/cut1	-3.514935	.8227615			-5.127518 -1.902352

/cut2	-2.486096	.6906565			-3.839758	-1.132434
/cut3	-1.954763	.6603636			-3.249052	-.6604739
/cut4	-.1739209	.6183478			-1.38586	1.038018

```

Iteration 0: log likelihood = -122.67317
Iteration 1: log likelihood = -119.05125
Iteration 2: log likelihood = -119.02575
Iteration 3: log likelihood = -119.02574

```

Ordered logistic regression	Number of obs	=	113
	LR chi2(8)	=	7.29
	Prob > chi2	=	0.5052
Log likelihood = -119.02574	Pseudo R2	=	0.0297

followthrough	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]	
additionalschoolservices	-.563386	.4114816	-1.37	0.171	-1.369875	.2431032
formalinhomeprovider	-.5750474	.4634951	-1.24	0.215	-1.483481	.3333864
informalinhomeprovider	.6675207	.4996464	1.34	0.182	-.3117683	1.64681
formalcommunityprovider	.1698685	.4268027	0.40	0.691	-.6666494	1.006386
informalcommunityprovider	.502643	.5821806	0.86	0.388	-.63841	1.643696
parentsupportgroup	-.6835145	.6095702	-1.12	0.262	-1.87825	.5112212
agegroup						
2	.0588725	.6284102	0.09	0.925	-1.172789	1.290534
3	.4771298	.8462441	0.56	0.573	-1.181478	2.135738
/cut1	-3.776469	.8347273			-5.412504	-2.140434
/cut2	-3.050465	.7306539			-4.48252	-1.61841
/cut3	-1.87905	.6533375			-3.159568	-.5985324
/cut4	-.4180253	.6183777			-1.630023	.7939727

```

Iteration 0: log likelihood = -116.20028
Iteration 1: log likelihood = -112.21037
Iteration 2: log likelihood = -112.17644
Iteration 3: log likelihood = -112.17642
Iteration 4: log likelihood = -112.17642

```

Ordered logistic regression	Number of obs	=	111
	LR chi2(8)	=	8.05
	Prob > chi2	=	0.4288
Log likelihood = -112.17642	Pseudo R2	=	0.0346

meetingneeds	Coef.	Std. Err.	z	P> z	[95% Conf. Interval]	
additionalschoolservices	-.139735	.4162303	-0.34	0.737	-.9555314	.6760614
formalinhomeprovider	-.6226619	.4655916	-1.34	0.181	-1.535205	.2898808
informalinhomeprovider	.6609095	.4885644	1.35	0.176	-.2966591	1.618478
formalcommunityprovider	.0019685	.4173241	0.00	0.996	-.8159717	.8199087
informalcommunityprovider	.4512362	.5705616	0.79	0.429	-.6670439	1.569516
parentsupportgroup	-1.038944	.6062797	-1.71	0.087	-2.22723	.1493424
agegroup						
2	.3954719	.6240845	0.63	0.526	-.8277112	1.618655
3	1.146349	.9024749	1.27	0.204	-.622469	2.915167
/cut1	-2.838964	.7450759			-4.299286	-1.378642
/cut2	-2.646092	.7237297			-4.064576	-1.227608

```

/cut3 | -1.795429 .6626189 -3.094138 -.4967199
/cut4 | .0848339 .6191943 -1.128765 1.298432

```

```

-----
Iteration 0: log likelihood = -110.02725
Iteration 1: log likelihood = -105.68679
Iteration 2: log likelihood = -105.63839
Iteration 3: log likelihood = -105.63835
Iteration 4: log likelihood = -105.63835

```

```

Ordered logistic regression      Number of obs   =      113
                                LR chi2(8)       =       8.78
                                Prob > chi2        =      0.3614
Log likelihood = -105.63835     Pseudo R2      =      0.0399

```

```

-----
timecmavalible |      Coef.   Std. Err.   z   P>|z|   [95% Conf. Interval]
-----+-----
additionalsschoolservices | - .3097914   .424061   -0.73   0.465   -1.140936   .5213529
formalinhomeprovider | - .6198508   .4736206   -1.31   0.191   -1.54813   .3084286
informalinhomeprovider | .8944011   .5103947   1.75   0.080   -.1059542   1.894756
formalcommunityprovider | .3778746   .4342612   0.87   0.384   -.4732618   1.229011
informalcommunityprovider | .4515907   .5941338   0.76   0.447   -.7128902   1.616072
parentsupportgroup | - .8331795   .633749   -1.31   0.189   -2.075305   .4089456
|
agegroup |
2 | - .8315842   .7199956   -1.15   0.248   -2.24275   .5795812
3 | - .3121263   .9251078   -0.34   0.736   -2.125304   1.501052
-----+-----
/cut1 | -4.382633   .9133347   -6.172736   -2.59253
/cut2 | -4.085927   .86697   -5.785157   -2.386697
/cut3 | -3.108259   .7771133   -4.631373   -1.585145
/cut4 | -1.006659   .7092962   -2.396854   .3835365
-----

```

```

Iteration 0: log likelihood = -145.8711
Iteration 1: log likelihood = -139.06774
Iteration 2: log likelihood = -139.00263
Iteration 3: log likelihood = -139.00255
Iteration 4: log likelihood = -139.00255

```

```

Ordered logistic regression      Number of obs   =      112
                                LR chi2(8)       =     13.74
                                Prob > chi2        =      0.0889
Log likelihood = -139.00255     Pseudo R2      =      0.0471

```

```

-----
goals |      Coef.   Std. Err.   z   P>|z|   [95% Conf. Interval]
-----+-----
additionalsschoolservices | - .6204571   .4043401   -1.53   0.125   -1.412949   .1720348
formalinhomeprovider | - .4107542   .4542135   -0.90   0.366   -1.300996   .479488
informalinhomeprovider | .0817335   .4426633   0.18   0.854   -.7858707   .9493376
formalcommunityprovider | - .1243702   .4043678   -0.31   0.758   -.9169166   .6681762
informalcommunityprovider | .8821574   .4982603   1.77   0.077   -.0944148   1.85873
parentsupportgroup | - .2098169   .5866203   -0.36   0.721   -1.359572   .9399378
|
agegroup |
2 | .2807687   .5806766   0.48   0.629   -.8573365   1.418874
3 | 1.655234   .7728369   2.14   0.032   .1405011   3.169966
-----+-----
/cut1 | -3.343343   .7487438   -4.810854   -1.875832
/cut2 | -2.470041   .6501596   -3.744331   -1.195752
-----

```


/cut3	-.8170858	.5882743		-1.970082	.3359106
/cut4	1.250109	.5958267		.0823105	2.417908

```

-----
Iteration 0:  log likelihood = -143.94857
Iteration 1:  log likelihood = -137.33258
Iteration 2:  log likelihood = -137.26583
Iteration 3:  log likelihood = -137.26576
Iteration 4:  log likelihood = -137.26576

```

Ordered logistic regression	Number of obs	=	112
	LR chi2(8)	=	13.37
	Prob > chi2	=	0.0999
Log likelihood = -137.26576	Pseudo R2	=	0.0464

```

-----
              overalld2d |      Coef.   Std. Err.      z    P>|z|     [95% Conf. Interval]
-----+-----
additionalchoolservices |   .3433216   .3816594     0.90   0.368   - .4047171    1.09136
  formalinhomeprovider |  -1.027828   .4643997    -2.21   0.027   -1.938035   - .1176215
  informalinhomeprovider |   .444305    .4449148     1.00   0.318   - .4277121    1.316322
  formalcommunityprovider | .0869731    .3984814     0.22   0.827   - .6940361    .8679824
informalcommunityprovider | -.060269    .5123824    -0.12   0.906   -1.06452    .9439821
  parentsupportgroup |   1.154746   .6604837     1.75   0.080   - .1397783    2.44927
      |
      agegroup |
      2 |   .941529   .554457     1.70   0.089   - .1451868    2.028245
      3 |   1.534006   .7458734     2.06   0.040   .0721211    2.995891
-----+-----
              /cut1 |  -2.417181   .7004221    -3.44   0.001   -3.789983   -1.044379
              /cut2 |  -1.809296   .6251813    -2.90   0.004   -3.034629   - .5839631
              /cut3 |   .0954781   .5529509     0.17   0.867   - .9882858    1.179242
              /cut4 |   1.815921   .5752632     3.16   0.002   .6884258    2.943416
-----

```

Appendix C

Digest of responses to open-ended question 1, by theme

What type of advice would you offer to families or parents of children with special needs that are new to the program?

Be patient/wait (6):

- Be patient
- Be patient
- Be patient. There are a lot of steps to go through to get equipment.
- To have patience, the miracles will happen.
- Be patient, the process took a long time.
- Don't expect anything to happen in a timely manner.

Self-Advocate (30):

- Advocate for your child
- Be vocal about your child's needs.
- Be specific and try and come up with specific needs, specific goals, and ways you will reach those goals.
- Keep things attainable and realistic, yet be the best advocate for your child.
- Advocate in your child's best interest
- Advocate for your family
- Also the services and resources available to you at that time.
- Advocate for your child
- Advocate for your child
- Get a list of what services can be provided
- Advocate for your child
- Do your own research on your own for additional help and services
- Don't be afraid to advocate for your child and to ask questions or bring up concerns.
- Advocate
- Speak out your needs
- To ask for what you need
- Get all the info you can.
- I would say to ask for anything you feel might benefit your child and be persistent.
- You are going to need to learn how to get through red tape to get what your child needs.
- Keep open lines of communication open
- Be creative in how you utilize services – it can really benefit your child to think outside of the box.
- Be open about all possible needs. Don't be afraid to ask.
- If something isn't working out ask for a change.
- Seek out everything you can.
- Be proactive and persistent.
- Check everything available to you.
- Need to request info on what services are available and what other families are receiving.
- It doesn't hurt to ask for items, suggestions.
- Don't be afraid to ask for something – might not get it but always ask.
- Follow your instincts!

Program (8):

- Don't bother with the time, energy or paperwork
- This program is a joke. We have not been able to use it for anything.

- Try hard to get both parent at the 6-month meetings. It can be overwhelming to look at the costs of the program and all the goals and resources.
- That the names of the services are confusing so keeping a file helps to keep things straight and talking through the extensive process can be daunting.
- This is a great place for resources or to reach out if you have questions.
- Just take advantage of it and it's a great program.
- Also, the differences in what families receive are so frustrating. To provide coats and boots for one kid but not sensory items for another is so ridiculous! Why are this so different?
- Pursue the program even if someone tells you that your child will not qualify (our case and we went w/o services for years due to mis-information)

Seek Support/Connect w/ Other Families (11):

- Get as much advice as possible
- Join the Autism Society to be around other kids with special needs and their parents to be social and get out into society.
- Start as early as possible with the county services and support systems
- Talk with other families to learn how they use the program.
- Join Facebook groups
- Get info from other parents of children with special needs.
- Connect to a parent support program – there are so many things not one place is aware of for resources/programs. Parents are the best resource.
- Get involved with families that have gone through a similar experience.
- Review the available resources guide! Join local special needs Facebook groups to get ideas about available resources.
- Do not be scared to ask for help.
- Ask what services are available to you – I'm always learning about different services available from other parents, NOT from our County worker.

Service Coordinator (15):

- Be sure to share all your concerns with your case manager. They are knowledgeable about resources/services to help you.
- Be open and honest – develop a good relationship with your case worker.
- Keep close contacts with coordinators
- Stay in touch with your coordinator.
- Make yourself aware of what assistance is available. It more often happens that you find out about a service or product that would be helpful and then you have to convince your service coordinator that it would be beneficial. Ideally, you could discuss a concern and your service coordinator would suggest options that would be helpful. But this does not seem to be the case unfortunately.
- Communicate frequently with your child's service coordinator. Do not hesitate to ask questions or to express frustrations or newly recognized needs you have. They are experts and willing to try to get your family the help they need. They may surprise you!
- Katie Miller and Rebecca Messnick are amazing! We will miss them!
- Make sure you do your own research because the service coordinators don't make suggestions about what may be helpful.
- I must admit, I am very impressed with the services that you offer. Your work Ted W. answered my phone call every time I called and he is invested in his client.
- Be sincere with and share your concerns, hopes for your child with your service coordinator.
- Work with your coordinator be creative in asking for services. Be patient. Keep the communication going.
- Ask your coordinator about what's available for your child now and in the future.
- Run every purchase idea for your child through your case worker, the county might be able to cover it.

- Our service provider continues to offer new information to us as my child grows and his needs change. It has helped to just keep asking our service coordinator questions as we venture through his life/experiences.
- Ask your service coordinator a lot of questions. Ours has been helpful in answering them and/or helping direct us to resources.

Ask Questions (22):

- Ask many questions
- Ask ask ask questions!
- We were really struggling to meet the needs of our son. Ask questions and they can help assist you.
- Ask questions – so much info and services are offered by Waukesha Co vs Milwaukee. Milwaukee Co runs out of funds and provides limited services.
- Ask questions.
- Ask questions and always take the best interests of your child into account.
- Ask questions
- Ask questions and it's okay to ask for clarification.
- Always ask questions.
- Ask questions
- Don't be afraid to ask questions
- Ask questions
- Ask questions
- Ask questions
- Don't be afraid to ask for something
- Don't be afraid to ask for something
- Don't be afraid to ask questions.
- Ask a lot of questions.
- Ask questions about everything you don't completely understand. The first year we did it, we barely asked for anything because I felt "there are others who need it more". The second year a YMCA membership and swim lessons was paid for and it changed my son's life tremendously (was afraid to put face in water – now goes under water!)
- Ask questions no matter how trivial it seems. Your coordinator may know who to direct you to or have an alternate idea for you.
- Ask questions you don't know what services are out there to help you and your child until you do.
- Ask questions consistently. Information on what services can be covered is not always provided. You have to ask for things and be prepared to wait to receive them.

Specific Services/Resources (10):

- Sensory Rooms in the city
- Gym Memberships
- Summer Camps
- Check list of camps
- Get all the services you can to help your child get through his/her disability.
- More training for parents for physically aggressive children
- There are many resources available that could be beneficial
- Register for respite care, the breaks help!
- It takes awhile to figure out what program and services are the most beneficial for your child. Sign up for everything and see if it works, give it a fair trial and if not right for you or your child move on.
- Ask everyone to be a therapist (i.e., swim coach, teachers, camp counselors). They are hard to find.

Organize Paperwork (2):

-Keep a notebook

-I believe it is most important to write down needs, level of safety concerns and documentation or journal of successes and non-successes. I also felt more in control when I put each provider in a file box (portable) even down to physician and personal info on child and history. PTSD is real and happens in these cases.

Misc (1):

-Don't put yourself in a position where reimbursement is promised. This has put me in economic hardship.

Appendix D

Digest of responses to open-ended question 2, by theme

What services or support were most helpful to your family?

Respite (32):

- Respite
- Respite
- Respite
- In home respite. Without it, we would be in a very bad place.
- Respite
- Respite
- Respite
- Respite
- Respite
- Respite
- Respite
- Respite
- We appreciate the respite care. It helps give us a break and know that our child is safe.
- Respite
- Respite
- Respite
- Additional respite care
- Respite care financial assistance
- Respite
- Respite
- Respite
- Respite care
- Respite care for our daughter
- Directed us to respite provider.
- Respite care
- Respite
- Respite
- Respite
- Respite
- Respite
- Respite
- Respite
- Respite
- So far there hasn't been much help other than respite worker. I have to work more to get items she needs and fight so hard to get services and items causing more stress and frustrations well as financial hardship. Very disappointed.

Program in General (2):

- We have had a very frustrating experience with this program.
- Having a connection to so many resources/services that we may use now or in the future.

Music Therapy/Lessons (7):

- Music
- Music Therapy

- Music Therapy
- Music Therapy
- Music Therapy
- Music Therapy
- Music lessons

Personal Care (2):

- Personal care workers
- Personal care workers

Home Modifications (2):

- Home Modifications. It was getting extremely difficult to care for my son. He was getting to heavy and the Waiver program helped us make our lives easier.
- Home Modifications

Camps (5):

- Summer Camp
- Summer Camp
- Camps
- Summer camp
- Day camps during summer break

Adaptive Aids/Equipment/Sensory Items (10):

- The program and our coordinator have been extremely helpful in small ways – obtaining GPS monitor, noise canceling headphones, but it would be really great if in person social groups and camps would run during his time in the program.
- Getting a chair lift
- An adaptive bike! It has been a blessing to give him some independence and lets him feel like a regular kid. We could never have afforded one alone.
- Sensory items purchased by the program for our son.
- Adaptive bicycle
- Assistance with providing assistance purchasing equipment to improve my son’s quality of life.
- Sensory equipment
- Sensory items (swing)
- Equipment to help our son in his day-to-day activities have also been greatly appreciated.
- Mobility devices: wagon, bike, etc.

Diapers/Wipes (3):

- Baby wipes? That’s all we get
- Diapers/wipes
- Wipes

Zoo Pass/Memberships (5):

- Zoo pass
- Assistance with providing assistance purchasing memberships to improve my son’s quality of life.
- Zoo pass
- Zoo pass

-Zoo pass – low guilt if we have to leave early after arrival due to health/mood of our son.

Sensory Club (2):

- The sensory club
- Sensory Club Membership

Social Skills Groups (5):

- Social services
- Social Group
- Social Skills
- Social skills group
- We have only just started services and thus far a social group is all we have been involved with.

Daily Living Skills/Activities of Daily Living (8):

- So far there hasn't been much help other than DLS worker.
- DLS
- DLS
- DLS
- DLS
- DLS
- In-home ADL, especially being flexible once things became more challenging with the COVID pandemic. Paige quickly approved extra hours and a new schedule and facilitated services by multiple agencies.
- ADL

YMCA (8):

- YMCA – sport outlet is so important
- YMCA
- YMCA
- YMCA
- YMCA
- YMCA Membership
- Y Membership
- YMCA membership

Swimming (4):

- Swimming
- Swim lessons
- Swim lessons! Not only did he start going under the water – he now takes showers and washes his hair on his own!
- Thru this program swimming

Hippotherapy/Horseback Riding (6):

- Equine Therapy
- Horseback Riding
- Hippotherapy
- My son recently began Lifestriders through the CLTS Waiver. It has been a game changer for his happiness and confidence.

- Equine therapy
- Horse therapy

Therapy (5):

- In-home therapy
- Therapy
- In-home therapy
- Therapy
- Art therapy

ABA (5):

- ABA Therapy
- ABA Therapy
- ABA Therapy
- In home ABA. Without it, we would be in a very bad place.
- ABA Services

Financial (2):

- Honestly, the financial coverage. As parents, we have done most of the searching for appropriate services and programs for our child. Having the service coordinator help us find a way for us to afford services has been crucial.
- Financial help for some safety items.

Service Coordination (7):

- Having an amazing case worker like Leslie Zersen.
- My service coordinator has been so helpful guiding us through finding resources that have been beyond vital and life changing in my con's recovery and growth and success.
- Support for always having our case worker available
- Our coordinator was kind and I never felt judged or chastised even when I was upset and in crisis. When she couldn't answer my needed help she organized a meeting with her supervisors. Tiara Daniels is good at her job.
- Ted has been an amazing support during this time.
- When the Waiver worker got us help in getting the things for the child
- We love our coordinator, she's been a good support – Amanda Hutchinson

Child Care (2):

- Child care services during virtual school days
- Support for helping while we are working (daycare will not take our son)

Misc (27):

- Adaptive drivers ed
- Vehicle modifications
- Formula
- Tracker services
- Coordinated care services
- Mentor Program
- Everything
- May sounds silly but get a copy of the ADRC book at home. You can find some unthought resources/avenues to ask for help

- In-home supports
- Hospice
- Support with severe food allergies
- Support with one child's communication delays.
- All services received have been helpful
- Yoga
- Pink Umbrella
- JCC (classes and upstream arts)
- PT/OT
- SLP through Forward Health and private insurance
- Summer Programs
- Autism Society of Wis parent support group and the Facebook page.
- Family outings for kids and families of kids with special needs and awesome – when there is no COVID
- Gemini program
- Care givers in home
- Skyzone trampoline
- Broadscope
- Katie Beckett
- Was not able to use most due to COVID.

Appendix E

Digest of responses to open-ended question 2, by theme

No Gaps (5):

- no gaps
- no gaps
- no gaps
- no gaps
- We experience zero gaps. Everyone works really hard to stay in touch and maintain updates – its been great!

Service Coordinators (4):

- We need more support to find services from Ted – our service coordinator
- Service coordinator answers my question but doesn't have our best needs in mind – she knows about resources but doesn't share them. It is almost like hoping you won't ask.
- There are quite a few in our perspective. We have found the program to be a lot of work and stress but with little benefit. One specific – our coordinator does not provide answers constantly has to ask their supervisor and imposes more work for us.
- There are gaps in the communication in the program. Changes to respite are allocation were not communicated. Changes to PPL were not communicated well. Important program changes should come via US mail, opportunities can come via email.

Understanding What is Covered/Program (16):

- When multiple agencies are involved, knowing who will cover certain things ex: adaptive drivers ed
- Maybe have additional info/options/ideas for the specific disability
- Streamlined toward specific disabilities
- Availability of services to give as examples for families to hear or choose from
- It would be helpful to have more detailed information about what the waiver program can help with.
- I personally would ask for more things/services that I could get from Waiver if I were more aware of what is available through the Waiver
- Understanding the shared contribution.
- I struggle with feeling like I have a true picture of what is available and find some service providers seem to struggle.
- Not necessarily any issues but I don't always know the right questions to ask.
- Confusing about who covers various medical equipment, somethings have to go through insurance first and be denied before covered by CLTS. Other things are covered straight away.
- Would also appreciate more transparency w/ billing – line items, details, expected amount for next month, etc.
- Running out of funds each year prior to year-end.
- Just fear of unknown – what aren't we utilizing that could benefit our son?
- Some of the stranger or less straightforward items are tough to acquire. Also, the new respite program is confusing and hard to navigate.
- Some sort of reference, guide to ideas/options

Lack of Qualified Providers (12):

- I need a care worker that is qualified to help is a few days a week. I cannot find qualified help for my son at a compatible wage. Especially during the summer, I need someone. My husband and I need to work full-time to support our family.
- Not enough providers for children

- Difficult to have families in charge of funding supports. Very time consuming for families and they often go without because they cannot find people to hire.
- Availability of therapists
- Need more therapists
- Throughout this process prior to COVID I had much anxiety when Spring came and there was still no summer plan for my son – then programs were quickly filled up and by May there was no way to get help/structure to my son. Severity needs to factor in to this timing.
- The hardest part is finding therapists/respite care providers. There just are not enough staff wherever we look. Not a problem that can be solved easily, just tricky for those needing help/providing consistency.
- Limited care providers
- Variety/network of respite providers
- Finding services for children over 11 years of age but younger than 18 years.
- Yes, because of COVID and lack of personal
- Right now, none. Earlier in the year and the second half of 2019 we had terrible problems with our service provider being able to provide caregivers. Our daughter went without full-services for 6-9 months because Genesee Community Services being unable to provide us enough care workers.

Specific Service Not Available, Delayed, or Denied (22):

- Help with bathing and daily needs
- Several items that we requested for our child were not able to be covered
- When you lose a therapist or respite person
- Virtual respite is something that needs to be explored and covered
- Yes, we were receiving social skills and activities of daily living and now he isn't. Still waiting to hear back.
- Mentor Program
- Parent Training
- Childcare or 3K programs for working parents – nothing available full-time
- We have found there is lots of programs and help available for children with severe disability, low function skills – as there should be, but difficult to find appropriate services and programs for a high functioning child that still faces many challenges.
- Lack of programs that fit my child's needs
- Wish WAC or YMCA was funded
- Swim lessons – life skill (no funding avail)
- My child with Down Syndrome really could use additional SLP as 1x/week 30 minute sessions from school has always been and will continue to be ineffective.
- Coverage for items not covered by insurance but also not available through contracted suppliers (or available but not suited to individual's use for reasons such as allergies, specific situation, etc.)
- Some services are cheaper from vendors not supported by the program. There should be some flexibility with the funds allotted to a family. Overall program is very helpful
- Although I understand the liability behind it, the definition of "restrictive" in regards to harnesses and straps has been taken very literally for some of our requests. (Other requests, the "process" has taken into consideration our son's need for such "restraints" so I appreciate that).
- Dental care! That is a huge problem. I have one choice for care and this dentist has many bad reviews. The office is not COVID compliant. I wish there were more options – even paying a copay for a better provider.
- Coverage for supplements/vitamins
- Hippotherapy is not covered by the Waiver in Waukesha Co but is in surrounding counties.
- Would love to have great access to hippotherapy – therapeutic horseback riding. Lifestriders through the years has been terrible with follow through, no return phone calls or program start up dates. I'd like it to be an option for us but this organization is either too busy or highly disorganized for service.
- Coverage for therapeutic riding equestrian sessions (and not just the social skills groups @ Lifestriders)
- For hippotherapy only group lessons are covered. Would be much more beneficial if one on one with an OT was covered. Because of her Autism my daughter cannot participate actively and follow group directions.

Waitlist/Slow to Start for Services/Timeliness (6):

- The time it takes to get home modifications completed
- Long waits for services and children are disadvantaged because of this.
- Service coordinator is timely sometimes the providers aren't as responsive or don't have necessary (expected) staff.
- Length of time. Our son regularly runs toward a very busy road in the back of our house. We have now been 1 ½ years in the process of having a fence put up for his safety. All the hoops to jump through are SO slow!
- Yes. A long wait. Our coordinator does not appear to have a solid grasp on the program. She is not providing suggestions.
- There are so many hoops to jump through to get services. Many times, the contracted providers don't have the equipment needed so we go without. We are still waiting 9 months later for resolution on several health needs.
- Declined/approval of requested items and the actual payment of the approved items/services is extremely lengthy and always requires "manager approval". Would prefer to just go to the manager myself then or have my service provider be able to approve some things.

COVID (7):

- Yes, because of COVID and lack of personal
- Currently way too many to list. The current situation we are in with COVID (beyond anyone's control) has made these kids like my son (on the autism spectrum) so vulnerable and unable to experience social skills in a real setting. I fear that these kids will fall too far behind and unable to recover.
- Think COVID-19
- Yes because of COVID
- COVID
- COVID – respite and DLS help
- Gaps created this year more because of the 2020 pandemic. It has been tricky to understand our benefits and all our payments for services as we weren't getting a bill, then did. Some services shut down so we weren't able to even get them.

Misc (5):

- This whole waiver is a "gap"
- LOL
- Don't know
- When we moved to Waukesha Co we had about a year gap.
- Behavioral