

Waukesha County Department of Health and Human Services

2018 Children with Special Needs Consumer Quality Assurance Survey





Report prepared by:

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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 2019, **Neighborhood Analytics, LLC** analyzed the results of the 2018 wave of the ongoing Children with Special Needs (CSN) Consumer Quality Assurance Survey and compiled this report.

The CSN Consumer Quality Assurance 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 case manager performance, perceptions of parent/guardian involvement, perceptions of outcomes, and preparedness for transition to adult services.

In 2018, 810 mail surveys were distributed; 149 completed surveys were returned, yielding a response rate of 18%. By comparison, the response rates for the 2017 and 2016 waves were 17% and 24% respectively. The industry standard return rate for mailed paper surveys is \sim 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. This wave included some changes to question wording designed to elicit more precise responses; these changes are clearly indicated in the body of the report and their impact is discussed.

Major Findings

- Aggregate satisfaction with multiple dimensions of case manager performance remains high and relatively stable over time.
- Average levels of satisfaction with program effectiveness continue to trend downward; fewer respondents are seeing improvements in day-to-day functioning, and fewer respondents see participation in programs as contributing to reaching their most important goals.
- Perceived self-involvement in service plan development/outcomes remains high, and has remained relatively stable across the past three waves.
- The proportion of respondents indicating that their child/family experienced severe health and/or safety concerns while waiting for services remains low.
- Families reporting having experienced concerns while waiting for services were more likely to say they were able to independently cope in 2018 when compared with 2017.
- Most respondents with children who were 17 as of July 1st 2017 said they are prepared for transition to adult services, and the vast majority strongly agreed that their case manager had assisted with preparation.

Full Results

The first question 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 stable over time. Figure 1b shows a slight increase in the proportion of respondents answering "strongly agree" over past years.

I am involved in the development of my child's Service Plan and Outcomes [average response (1=strongly disagree; 5=strongly agree), 2016 to 2018] 5 4 3 2 1 2016 n = (114) 2017 n = (88) 2018 n = (144) -Average Response 4.6 4.5 4.7

Figure 1a

I am involved in the development of my child's Service Plan and Outcomes [all response categories, 2016 through 2018] 100% 75% 50% 25% 0% 2016 n = (114) 2017 n = (88) 2018 n = (144) ■ Strongly Agree 72 57 104 ■ Agree 38 26 34 ■ Neutral 2 3 4 ■ Disagree 1 1 2 1 ■ Strongly Disagree 1

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 both the average response and the overall distribution of responses have remained constant over the past three years.

Figure 2a I am provided with useful feedback, information, and resources in relation to my child's needs [average response (1=strongly disagree; 5=strongly agree), 2016 to 2018] 5 4 3 2 2016 n = (115) 2017 n = (89) 2018 n = (143) Average Response 4.1 4.1 4.1

I am provided with useful feedback, information, and resources in relation to my child's needs [all response categories, 2016 through 2018] 100% 75% 50% 25% 0% 2016 n = (115) 2017 n = (89) 2018 n = (143) ■ Strongly Agree 50 36 59 ■ Agree 39 37 52 ■ Neutral 16 9 22 ■ Disagree 8 3 6 ■ Strongly Disagree 2 4 4

Figure 2b

The third question asked respondents to agree or disagree with the following statement:

"My case manager 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 stabilized after dropping slightly between 2016 and 2017. Figure 3b shows slight polarization in the distribution of responses to this question when compared to last year; a small increase in the proportion of respondents answering "strongly agree" is offset by a similar increase in the proportion of respondents answering "disagree".

Figure 3a My case manager helps me to better understand the abilities and limitations for the programs that we are currently participating [average response (1=strongly disagree; 5=strongly agree), 2016 to 2018] 5 4 3 2 1 2016 n = (115) 2017 n = (89) 2018 n = (143) -Average Response 4.4 4.1 4.1

Figure 3b My case manager helps me to better understand the abilities and limitations for the programs that we are currently participating [all response categories, 2016 through 2018] 100% 75% 50% 25% 0% 2016 n = (115)2017 n = (89) 2018 n = (143) ■ Strongly Agree 63 37 66 ■ Agree 38 34 43 ■ Neutral 8 11 18 ■ Disagree 6 4 12 ■ Strongly Disagree 3 4

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 (4.3) is closest to "agree". The average level of agreement has remained largely stable over time. Figure 4b shows a very slight increase in the proportion of respondents answering "strongly agree".

Figure 4a

My requests, questions, and concerns are responded to in a timely manner

[average response (1=strongly disagree; 5=strongly agree), 2016 to 2018]

5
4
3
2
1
2016 n = (115) 2017 n = (89) 2018 n = (142)

Average Response 4.4 4.2 4.3

Figure 4b My requests, questions and concerns are responded to in a timely manner [all response categories, 2016 through 2018] 100% 75% 50% 25% 0% 2016 n = (115) 2017 n = (89) 2018 n = (142) ■ Strongly Agree 65 40 76 ■ Agree 38 34 42 ■ Neutral 9 9 14 3 ■ Disagree 3 6 ■ Strongly Disagree 3 4

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 (4.2) is nearest to "agree". After a slight decline between 2016 and 2017, the average response to this question has stabilized. Figure 5b shows a very slight increase in the proportion of respondents answering "strongly agree".

Figure 5a Follow-through to my requests, questions, and concerns are appropriate [average response (1=strongly disagree; 5=strongly agree), 2016 to 2018] 5 4 3 2 1 2016 n = (115) 2017 n = (89) 2018 n = (143)

4.2 -Average Response 4.4 4.1

Figure 5b Follow-through to my requests, questions, and concerns are appropriate [all response categories, 2016 through 2018] 100% 75% 50% 25% 0% 2016 n = (115) 2017 n = (89) 2018 n = (143) ■ Strongly Agree 62 36 74 ■ Agree 42 38 43 ■ Neutral 6 8 14 ■ Disagree 4 5 10 ■ Strongly Disagree 1 2 2

Question six asked respondents about their agreement or disagreement with the following statement:

"My case manager assists in meeting the needs of my child and family."

Figure 6a shows the average response (4.2) is closest to "agree", and that the average level of agreement with this statement has stabilized after a slight dip between 2016 and 2017. Figure 6b shows an increase in the proportion of respondents answering "strongly agree" when compared with the previous year.

Figure 6a

My case manager assists in meeting the needs of my child and family

[average response (1=strongly disagree; 5=strongly agree), 2016 to 2018]

5
4
3
2
1
2016 n = (114) 2017 n = (89) 2018 n = (142)

Average Response 4.4 4.1 4.2

Figure 6b My case manager assists in meeting the needs of my child and family [all response categories, 2016 through 2018] 100% 75% 50% 25% 0% 2016 n = (114) 2017 n = (89) 2018 n = (142) ■ Strongly Agree 65 40 78 ■ Agree 39 32 35 ■ Neutral 5 10 17 ■ Disagree 4 3 8 ■ Strongly Disagree 1 4

Question seven asked respondents to agree or disagree with the following statement:

"I am satisfied with the amount of time my case manager is available to my family."

Figure 7a shows that the average response (4.2) is closest to "agree". Consistent with several of the other questions, the average response to this question has bounced back after a slight decrease between 2016 and 2017. Figure 7b shows increased polarization in the distribution of responses when compared to the past year, with an increase in the proportion of respondents answering "disagree" offset by a similar increase in the proportion of respondents answering "strongly agree".

Figure 7a I am satisfied with the amount of time my case manager is available to my family [average response (1=strongly disagree; 5=strongly agree), 2016 to 2018] 5 4 3 2 2016 n = (114)2017 n = (87) 2018 n = (142) 4.4 4.1 4.2 Average Response

I am satisfied with the amount of time my case manager is available to my family [all response categories, 2016 through 2018] 100% 75% 50% 25% 0% 2018 n = (142) 2016 n = (114)2017 n = (87) ■ Strongly Agree 77 63 36 ■ Agree 42 39 35 ■ Neutral 5 6 21 ■ Disagree 3 1 5 ■ Strongly Disagree 1 5

Figure 7b

Question eight asked respondents to agree or disagree with the following statement:

"[My child was 17 years old as of July 1st 2017] My case manager has provided me assistance with the transition to adult services process."

Previous waves of this survey asked for responses from those whose "child is close to turning 18." The change in question wording introduced this wave (asking from responses only from those whose child was 17 years old as of July 1st 2017) 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 shown in Figures 8a and 8b are due to a smaller and more objectively defined eligibility requirement for answering the question.

Figure 8a [My child was 17 years old as of July 1st 2017] My case manager has provided me assistance with the transition to adult services process [average response (1=strongly disagree; 5=strongly agree), 2016 to 2018] 5 4 3 2 2016 n = (46) 2017 n = (34)2018 n = (10)Average Response 3.8 3.6 4.8

Figure 8b [My child was 17 years old as of July 1st 2017] My case manager has provided me assistance with the transition to adult services process [all response categories, 2016 through 2018] 100% 75% 50% 25% 0% 2016 n = (46)2017 n = (34) 2018 n = (10)■ Strongly Agree 17 9 8 ■ Agree 7 7 ■ Neutral 20 15 ■ Disagree 1 2 ■ Strongly Disagree 1

10

Question nine asked respondents to state agreement or disagreement with the following statement:

"[My child was 17 years old as of July 1^{st} 2017] I feel that as a family we are prepared for the transition to adult services."

Similar to the previous question, the eligibility requirement for providing a response to this question was tightened this wave. Additionally, the question was moved from the end of the survey to the middle. The resulting differences between this wave and the last in the average response and the distribution of responses displayed in Figures 9a and 9b are likely driven by these changes.

Figure 9a [My child was 17 years old as of July 1st 2017] I feel that as a family we are prepared for the transition to adult services [average response (1=strongly disagree; 5=strongly agree), 2016 to 2018] 5 4 3 2 1 2016 n = (41)2017 n = (34)2018 n = (10) 3.5 3.3 3.6 Average Response

Figure 9b [My child was 17 years old as of July 1st 2017] I feel that as a family we are prepared for the transition to adult services [all response categories, 2016 through 2018] 100% 75% 50% 25% 0% 2017 n = (34) 2016 n = (41)2018 n = (10) ■ Strongly Agree 7 6 2 ■ Agree 5 4 11 ■ Neutral 20 2 18 ■ Disagree 3 2 3 ■ Strongly Disagree 2

Question ten 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 10a shows a very slight downward trend in the average response to this question over the past three waves (down to 2.2 [closest to "disagree"] in 2018). Figure 10b shows that about 20% of respondents expressed some level of agreement with the assertion that they had to deal with extreme health and safety concerns while waiting to receive services, and that proportion has remained relatively stable over the past two waves. The continuing decrease in the average response has been driven by increasing certainty on the part of those who felt that their family had not experienced such concerns.

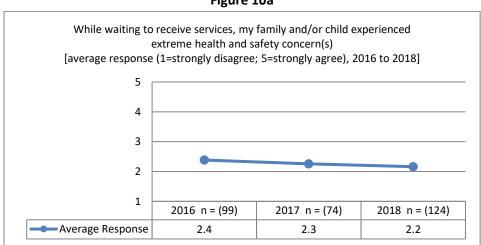
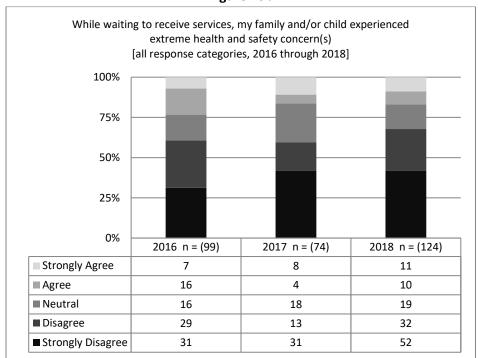


Figure 10a

Figure 10b



Among those who experienced health and safety concerns while waiting for services, a higher proportion was able to independently address those concerns in 2018 when compared to 2017. Figure 10c shows that the average response improved from 2.3 (closest to "disagree") in 2017 to 3.5 (closest to "agree") in 2018. Figure 10d shows that the overall distribution of responses shifted dramatically in a positive direction between 2017 and 2018.

Figure 10c

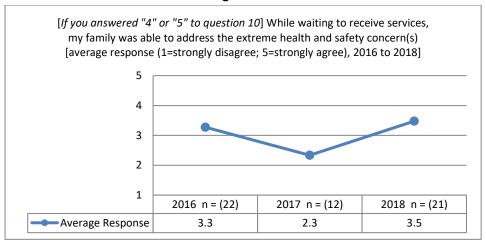


Figure 10d

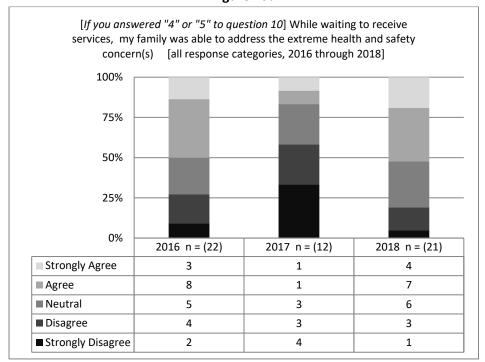
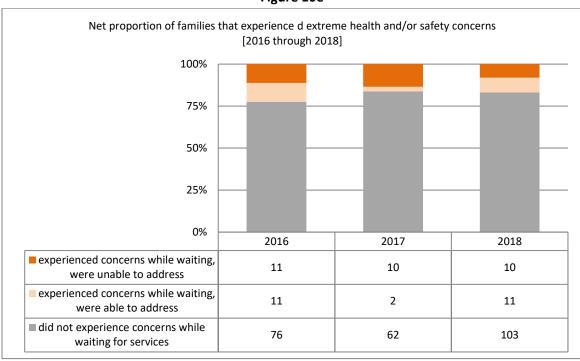


Figure 10e shows the complete picture; the proportion of respondents who agreed that they experienced significant concerns while waiting for services remained stable over the past two waves, but more of those families were able to cope in 2018.

Figure 10e



Question eleven 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 11a shows that the average response (3.7) is closest to "agree," but that the 3-year trend is increasingly negative. Figure 11b shows increases in the proportions of respondents expressing negative sentiment, and a decrease in the proportion of respondents expressing very positive sentiment.

My family's overall day-to-day functioning improved after we started to receive services through these programs [average response (1=strongly disagree; 5=strongly agree), 2016 to 2018] 5 4 3 2 1 2016 n = (113) 2017 n = (88) 2018 n = (135) -Average Response 4.1 4.0 3.7

Figure 11a

Figure 11b My family's overall day-to-day functioning improved after we started to receive services through these programs [all response categories, 2016 through 2018] 100% 75% 50% 25% 0% 2016 n = (113) 2017 n = (88) 2018 n = (135) ■ Strongly Agree 44 34 34 47 ■ Agree 29 50 ■ Neutral 16 21 34 ■ Disagree 5 1 7 ■ Strongly Disagree 1 3 10

Question twelve 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 12a shows that the average response (3.6) is closest to "agree," but that the overall trend over the past three waves remains slightly negative. Figure 12b shows a negative shift in the overall distribution of responses; less people strongly agreed that involvement with these programs contributed to reaching their most important goals, and more people disagreed.

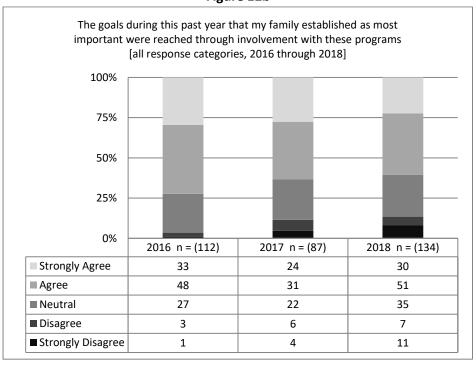
The goals during this past year that my family established as most important were reached through involvement with these programs [average response (1=strongly disagree; 5=strongly agree), 2016 to 2018]

5
4
3
2
1
2016 n = (112) 2017 n = (87) 2018 n = (134)

Average Response 4.0 3.7 3.6

Figure 12a





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?"

100 out of 149 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 A).

- 29 respondents specifically discussed specific resources and/or how to handle resources.
- 22 respondents discussed communication; more specifically, 10 of these 22 advised to ask questions.
- 12 respondents talked about case managers; generally, these responses centered around the idea that the case manager should be utilized often and viewed as part of the team.
- 12 respondents advised in the theme of remaining patient due to program waitlists and paperwork.
- 5 respondents stated that they were too new to offer advice.
- 4 respondents discussed seeking to understand the program.
- 3 respondents discussed early intervention as key to success.
- 13 respondents provided responses that could not fit into one of these categories above or another cohesive theme. Notable responses in this group include "Don't forget to take care of yourself," "Be appreciative," "Save receipts and stay on vendors to be sure they deliver services budgeted not that parental payments are billed by budget not services rendered."

The second open-ended question was as follows:

"What services or support were most helpful to your family? Where are the gaps in services/support?"

Out of 149 respondents, 94 provided responses to question 2; some respondents provided multiple responses. Similar responses to this question were grouped into themes for analysis purposes (refer to Appendix B for a complete digest of responses organized by theme).

"Most helpful"

- 44 respondents listed a service or support that was described as most helpful.
- 16 respondents mentioned respite as helpful.
- 7 respondents mentioned summer camp.
- 6 respondents mentioned case managers.
- 4 respondents mentioned social skills groups.
- 3 respondents mentioned obtaining items.
- 2 respondents mentioned music therapy.
- 2 respondents mentioned teachers.
- There were 10 other individual programs/services mentioned as helpful.

"Gaps"

- 36 respondents described gaps in services/supports.
- The most common gap (6 respondents) involved waiting for services; either a waitlist for the program, or a waitlist for a provider.
- 5 respondents indicated that they have been waiting for services to be set up.
- 4 respondents indicated a lack of resources and information about resources.
- 3 respondents said that support had been minimal.
- 3 respondents were looking for more financial support specifically.
- 2 respondents asked for swim lessons.
- 2 respondents asked for horseback riding.
- 2 respondents asked for a list of services covered to be provided.

Other

• 16 responses gave just the name of a service or their response could not be understood as a support or a gap. Of these responses, 11 mentioned respite, 2 stated "no gap", and the rest were one-off responses.

The third open-ended question was as follows:

"Based on your experience, please offer any other suggestions or ideas you may have for changes you'd like to see."

70 out of 149 respondents replied to this question; some respondents provided multiple responses. Similar responses to this question were grouped into themes for analysis purposes (refer to Appendix C for a complete digest of responses organized by theme).

- 43 respondents asked for more services—either new services, additional providers, more hours for existing services, or general funding for services. Respondents in this category also requested financial support, understanding of the family needs, and/or support during time spent waiting for services.
- 16 respondents asked for better access to information about the programs; what are the
 programs, what is covered, or what to expect. This category also included responses suggesting
 making information more available online so that families can find information and forms to be
 completed there.
- 6 respondents talked specifically about case managers and having more contact with them, having them provide more information and resources to them, and having them understand the programs better.
- 4 responses included compliments.

Appendix A

Digest of Responses to Open-Ended Question #1, Grouped by Theme

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

Case Manager:

- Take good notes and listen carefully to your case manager. The enrollment and application process are confusing.
- Make sure your case manager knows about your child's needs.
- Contact CM for help
- Be prepared for your case manager to change many times.
- Ask many questions as you are your child's best advocate. If you don't know something reach out to your CM they will gladly help you.
- Make sure your CM contacts you a few times per year.
- CM should explain more prior to the meeting about experiences and services offered.
- Get a good CM. We had asked for an item that was denied for being "unsafe" with no additional info. We followed up a few weeks later asking if anything could be done since this item was recommended by our PT. We were then told yes a letter from the PT. Why didn't they suggest this right away?
- Work as a team. They are there to support you.
- SW was very helpful and knowledgeable at explaining the program and how it can help us as a family. If you are not sure if your family could benefit still apply and get the info.
- Work closely with your case manager but also do your own research and stay involved in your kid's life.
- Work closely with your CM as they are your guide.

Resources:

- Find out about the programs available and then have a battle plan ready for your teen about how the programs go.
- Be alert on what your child needs and communicate it as best as you can.
- Be prepared for lots of paperwork and limited resources.
- Lifestriders
- Social Skills Class
- Look at everything available to help.
- Talk with other parents
- Think about needs as your child ages.
- Ask for different kinds of services available.
- Talk with other families about what programs helped them.
- Learn about all resources, especially respite and summer programs.
- Do your research, just because your child qualifies doesn't mean this is the best program for them.
- Attend SSAC meetings

- Join different parent support groups, there are online groups too! This is a way to learn about different resources and recreational too.
- Ask your CM questions they a great resource.
- Everything re: KB and its entities. It is very obscure and the only thing we know is that our child has secondary insurance.
- Save your receipts, like for swim lessons
- Be very specific in what you want for your program supports and make sure you know when to use your hours/programs by.
- Respite, home safety modifications, and therapy.
- Look for alternative solutions on the internet.
- Follow up with resources
- Follow through on ABA sessions
- Being a part of this has given us access to resources that will help us for years to come. We have learned about resources we didn't know existed. It was been a great help.
- The only program we have access to is respite so that program is easy to utilize. Bring up any issue with your CM as they may be able to help.
- Be creative when asking for services. If your need cannot be explained it will be difficult to get your child's needs fulfilled.
- Do research to support your request for assistance.
- Reach out to parents with kids on CLTS Waiver for advice.
- Be creative in thinking of different ways to utilize services. Also, the more open you are with your case manager, the better they can be in helping you.
- Connect with other families going through this.

Communication:

- Be prepared to self-advocate.
- Ask many questions about what services are provided. We were confused in the beginning and didn't know what it could help with therefore we did not pursue the program.
- Ask lots of questions. Often you don't know what is available and there isn't a list to choose from.
- Ask for what you need but prioritize.
- Ask questions
- Ask questions
- Ask questions
- Ask questions
- Ask lots of questions
- Ask lots of questions
- Ask lots of questions
- Be cautious, ask questions, and realize it will not make sense.
- Evaluate what your needs are as a family and the child.
- Make sure your questions get answered to your satisfaction

- Talk with other families about what they have had covered. We were told therapy was not covered and that another family told us it was. We had to look it up in the manual and SHOW the CM that it was supposed to be covered.
- Have an open line of communication with CM
- Keep communication with CM
- Ask for what is on their mind. Family services will then tell you if they can or direct you to who can.
- Ask about anything to see if it would be covered as a service. Don't assume it will not be.
- Key communication open with all that are helping. The CLTS program and one special therapist has helped my son immensely! Stay with the program the results will come, but this takes time.
- Regularly communicate with CM and ask questions.
- Keep in touch with your CM and ask questions.

Be Patient:

- Keep following up and don't depend on the financial support quickly.
- The CLTS Waiver is a program worth waiting for. It can be frustrating but overall it is an excellent program for support.
- Be patient while waiting.
- Everything takes time. Lots of red tape.
- Approvals can take weeks or months to process.
- Be patient
- Be patient
- Wait and be patient
- Be prepared to wait. Lots of waiting.
- Hang in there. It is not a quick fix and it takes many hours and people helping. Rely on other for help.
- Ask for what you need, keep asking if you don't get it
- When starting the program it takes time and patience to get some help. Their waiting periods till they have openings.

Understanding:

- Read everything
- Seek to understand since everything is not clear.
- Understand all of the programs offered.
- I find all the programs to be confusing.

Too New:

- None we haven't received any services yet.
- I have no advice because I have received nothing except T-19 which helps pay for services we have set up ourselves.
- Too new to say
- Too new
- We are new. Child on waitlist.

Early Intervention:

- Early intervention is key! Get the diagnosis as there are services out there.
- Reach out for help earlier.
- Get information when your child is born. Had no idea of services until summer so missed some child have used.

Words of Wisdom (Miscellaneous):

- Get ready for a rollercoaster.
- The program is easy to navigate and the services are lovely.
- Stay positive and everything is going to be ok because it worked for us.
- Don't forget to take care of yourself.
- Don't expect much
- Things will change as your child ages.
- Be appreciative
- Definitely worth applying for.
- Stay on venders to be sure they deliver services budgeted now that parental payments are billed by budget not services received.
- Terrible system with staff shortages.
- Get your renewal/waitlist paperwork back in a timely manner
- Say 'thank you'.
- Save receipts.

Appendix B

Digest of Responses to Open-Ended Question #2, Grouped by Theme

"What services or supports were most helpful to your family? What are the gaps in services/support?"

Most Helpful:

- KB has been amazing allowing us to continue services that our private insurance does not cover.
- Angel Sense and door alarms have been a godsend.
- Respite was very helpful.
- Home visits and discussions about needs were helpful.
- Social skills group4 and respite was helpful.
- Respite care and summer camp was helpful so that we could offer advice and what to expect.
- Music therapy has really changed my child's behavior for the positive.
- Respite has been the most helpful
- Respite was helpful but still hard to find providers that will work for \$10/hour.
- ABA is helpful but the gap is waitlisted for 2 years
- Social skills are helpful but very hard to find the right group
- Respite is helpful but hard to find the right people
- Very helpful with setting attainable goals
- Money for camps were nice but they didn't help with finding any camps. I had to do it all
 myself.
- Therapy and respite have been helpful
- Having respite hours and funding for summer camp was helpful
- Easter Seals camp and respite was helpful
- Installing ramps in the front and back of the house was helpful
- Mentor is helpful
- School teachers are a godsend.
- Physical aids were the most helpful
- Help to obtain items was helpful
- Respite was most helpful.
- The ability for my child to participate in summer camps and social groups has been helpful
- Loves music therapy but wish we could have funding for more than 2x/month.
- Respite and DLS were very helpful
- Working with CM
- Helpful to know that we have someone available to us as needs come up and to anticipate needs in the future.
- CM Nikki has been a godsend
- Respite and camp have been wonderful
- Having a support person is extremely peace of mind helpful
- Respite is helpful
- Contact with my CM Sara Geszvain
- Respite and fitness membership were helpful.
- CM Leslie Zersen is great. She makes the process "easy" for my family. I appreciate her knowledge, time, and patience.

- Summer camp, sensory supports, educational resources and social supports have been helpful.
- Equipment was most helpful.
- Respite is helpful however the assess to providers make using it difficult.
- Respite is the most beneficial specifically summer day camp.
- Not really understanding the County programs but once we got financial help it was a great help.
- One very special therapist dedicated to help our son.
- While on the program we had an extreme health and safety concern and we were able to address it in a timely manner thanks to the program.
- Respite is the biggest help. Transportation I feel could be improved. Options for transporting to therapies/appointments.
- Just started services and music therapy is being arranged.

Gaps:

- Not knowing what is available as it took time away from helping child.
- Social/Socialization programs are needed.
- No helpful resources and no information on how to expand the program to find resources or self-advocate.
- Gap is when a family just moves to the area, they have no connects to a case manager who would tell them where to go for help. There is no agency to contact while we wait on the waitlist.
- It's hard to know what will and will not be covered by insurance. A list of what is usually "not" covered would be helpful.
- My child needs more education about their issue from someone other than their parent.
- Waiting lists for everything. By the time our child comes to the top they will be an adult.6
- Gap was that we waited almost a year for services.
- Offer more income
- Offer more internal resources
- I am always having to contact the DHHS for help and they should be contacting me more.
- We have yet to have any services set up.
- Support has been minimal
- Need funding for summer/after school care. This allows us to keep our employment.
- Childcare was helpful but 10 hours per month was not sufficient.
- We have not received any support.
- We have been in the program for 6 months and so far, we have not received anything. This has been a waste of time filling out forms and meeting with a CM. They are coming out soon for a review but I don't know what we are reviewing because nothing has happened. More waste of time.
- No services have been received yet.
- Decrease the financial burden of supplies, access to respite care, and increase ability to meet the physical needs of our child.
- Wait time was the biggest gap.
- Need music therapy, swim, and horseback riding.

- Gap is from the CM not knowing or saying 'no' when it is just that they don't know.
- Lost respite while waiting.
- Gap was swim lessons and horseback riding.
- Have been on the waitlist since May 2018
- Gap was I was changed for respite we didn't use because my child was in the hospital and noone would provide respite post-op.
- I don't have an understanding of any other services than respite that are available to my Autistic child. Would be great if other services not covered by Forward Health might be addressed. An actual list of services would be helpful.
- I have yet to see how the LTS Waiver is helpful. I have meet with my CM 1-2 times now and nothing has come of it.
- Gap is not enough employees to help with special needs kids.
- Gap is families waiting for services.
- This program was almost useless to our family. All we used was camp and that was it. Please cover 1:1 swim lessons. They need this to be safe.
- The funding to provide adequate caregivers.
- Gaps couldn't be avoided.
- Gap is not enough respite workers (quality) and very difficult to find.
- Finding resources like respite care.
- Help with services available such as daily living skills. Still waiting to have respite set up.

Unknown:

- DLS
- Respite
- Was told that we should keep waiting and use Broadscope, ABA, and CCOP for safety items.
- Connecting parents with similar family
- The support to send my daughter to camps.
- Respite
- Respite
- Respite
- Respite
- Too new to say
- Wet wipes
- Respite
- ABA
- Respite
- Respite
- Music therapy
- Social skills groups
- Respite care
- Diapers, childcare, respite
- Respite
- Respite and swim lessons.

- No Gaps
- No Gaps

Appendix C

Digest of Responses to Open-Ended Question #3, Grouped by Theme

"Based on your experience, please offer any suggestions or ideas you may have for changes you'd like to see to the program."

Case Management:

- If there is no coverage for a need to have the case manager be able to explain how individual families can advocate for change.
- I am not sure what this program even does to help. Our case manager has been totally unavailable to us.
- Assign CM that can actually provide resources and recommendations.
- More contact with my CM throughout the year.
- Better CM that understand the program.
- CM spending more time with families so that they better understand family's needs.

Better Access to Information:

- Become more web-based so that forms can be completed online.
- We still have no idea what we can qualify for nor do we understand what we can use, please help us to understand.
- Provide specific information on what the County provides for families with children with special needs. Have specific information on the program where it is accessible to families considering the program, like online. We had no idea if this program would actually be helpful.
- Provide monthly updates on where you are on the waitlist.
- Have a comprehensive review where all providers of the child come together and discuss the family's situation and give recommendations.
- Please explain the different waivers and KB and how it is like or dislike Medicaid. We have no idea how they apply to our child's needs.
- A better list of services and items that are accessible.
- Still unsure of what the programs mean. Our child has been determined disabled, what does that mean?
- Provide families with a menu of options so they know what to choose from. This information is so hard to come by and so much is trial and error.
- Provide FAQ to parents.
- The dates on the ISP runs on the individual calendar year but respite is through Broadscope which is run on the calendar year so it is hard to track hours.
- An easy to read handout on all the services we qualify for and all the services available.
- Skype/video conferencing vs in-home quarterly appointments. Maybe yearly in the home otherwise would be helpful.
- I am unsure what is offered except Medicaid covering my deductible.
- Be able to tell families what kind of services or programs are available to the family once the family is in the program.

- Some kind of program handbook or guide. It would be helpful to see the guidelines, ideas, contacts of important people, etc.

More Services/Support:

- Add more socialization programs
- Add swim lessons
- Include funding for tutoring as this is a need for most families and we have to currently pay out of pocket for it.
- Provide CM for families who have just moved to the State to get connected with people who can help.
- Provide services while families sit on the waitlist.
- More hours and funding for respite.
- Would like to see RPM therapy added as a covered service. We have been paying out of pocket and have seen improvement with listening, writing, and focusing.
- More funding for camps and day trips.
- More ABA providers so that families can make a choice on provider.
- Transportation for children to Easter Seals in Milwaukee.
- Need in-home services for potty training.
- Link siblings together. The lack of this took planning time away from child in need.
- YMCA membership and class to work on strength and coordination.
- Shut it down. Give the money to an outside organization private that can manage them, understands needs more clearly for families and has current up to date platforms – web-based services.
- Give families support. We have not even been assigned a CM. No follow up. Nothing.
- Broken system. Just not enough funding or expertise to go around.
- Offering technology like IPADs, etc. since the child is homeschooled and we cannot obtain on our own to help with communication.
- Decreased wait time would of greatly improved my child's independence and development.
- Provide access to support groups.
- Fill needs faster.
- Interact children with the same needs as yours.
- It is difficult to find quality workers.
- Difficult to find workers especially PCWs
- Increase in childcare hours when both parents work.
- The process for medical equipment takes forever.
- Getting charged for respite that we didn't use is ridiculous.
- Bill based on services received instead of budgeted. So unfair when most hours missed are not a family's choice.
- Swim lessons covered
- Dog Services covered
- Offer more services including art therapy, music, hypo, and anything that helps physically or emotionally with the kids.

- Wish monies could be spent on activities and therapy services that are really necessary for our child i.e. swim therapy at Y, outside SLP, and other curricular activities.
- Everything takes a long time to process. We are no longer on the waitlist but we have not received any support or services even after 4 months.
- I understand that things take time and there are procedures to follow but I feel that the time it will take for my family to actually receive some of our "eligible items" is going to be lengthy.
- We are very pleased with our CM and the support we've received. We'd love to see therapeutic horseback riding funded as well as more than one option funding for same need (i.e. child might need more than 30 min/week activity to support goal to develop social skills).
- The County should pay the subscription to Care.com and allow all families access to it as different people have different levels of experience.
- Cover swim lessons as this is a concern for most parents.
- Reward the super therapist. It can be a struggle to get to one or two that really make a difference.
- It can be very hard to estimate the amount of time a child will be sick and out of school and with how the program is set up that estimate is very important. I would like to see the program more based on what is actually needed verse estimates.
- Biggest challenges are finding respite workers and frustration in dealing with J&B Medical supply.
- More support for special classes like adaptive swimming and gymnastics.
- More support in the areas of help sp needs kids be able to do things that neuro-typical kids can like adaptive bikes, swim lessons, sports programs, etc.
- Keep up the good work but expand services so there is no waitlist time.
- More accessible for swim lessons as it is a safety concern. Coordination with local police and sheriff regarding elopement/autism.

Compliments:

- Very thankful to the program to helping us with home modification.
- I am happy with the communication that is sent to us.
- Great staff! Ted was the best.
- Too new to say
- Happy with the program