

2023

Children with Special Needs

Consumer Quality Assurance Survey Report



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Executive Summary

Waukesha County Department of Health and Human Services (HHS) completes an annual Consumer Quality Assurance Survey within the Children with Special Needs (CSN) program area.

The CSN Consumer Quality Assurance Survey is part of an ongoing commitment to continuous improvement and quality service. The survey consists of a questionnaire that was developed as a means of gathering feedback from the families we serve. HHS evaluates and analyzes survey results to identify what is working or not working in practice. The results from the survey are used to guide next steps regarding improvements in service coordination practices, parent/guardian (caregiver) involvement, and program outcomes.

The Children’s Community Options Program (CCOP) Advisory Committee (formerly known as the Special Services Advisory Committee) has been instrumental in the annual success of this survey. The results of this survey are reviewed with committee members for further discussion and recommendations as to the prioritization of possible program enhancements. We encourage participation in the committee by the caregivers of any child enrolled in the program, members of the community, providers who serve children/youth, and voting committee members as we value the opinions of all whose lives are impacted by a child with special needs. CCOP Advisory Committee meeting dates, times, and agendas can be found at the following location:

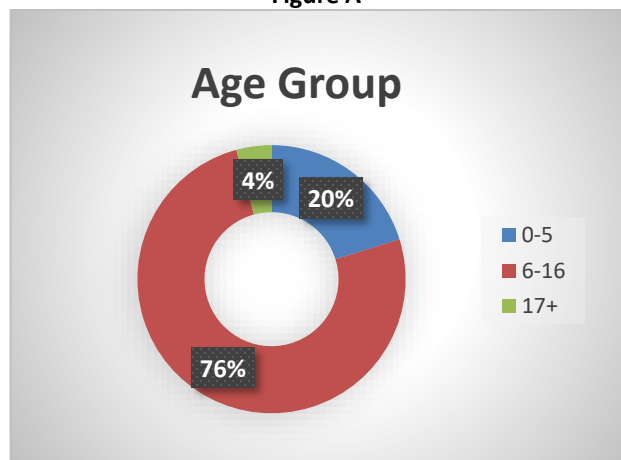
<https://www.waukeshacounty.gov/meetings/childrens-community-options-program-ccop/>

Survey administration began in 2016. In 2017-2020 a data analytics group compiled and analyzed the results. HHS now oversees this role and provides the survey to the caregivers of every child who receives ongoing CLTS services or only receives Children’s Community Options funding from the CSN unit within that calendar year. If a family has more than one child involved in CSN program, they are able to complete the survey for their experience with each individual child. Completion of the survey is voluntary and anonymous.

To better understand the varying needs of children and families by age, caregivers were asked to: ***“Please select the age group that your child was in as of July 1st, 2023.”***

A total of 213 caregivers responded to the age group question, with the findings shown in **Figure A**. Most caregivers (161) reported their child was in the 6-16 age group, (43) indicated their child was aged 0-5, and (9) said their child was 17+.

Figure A

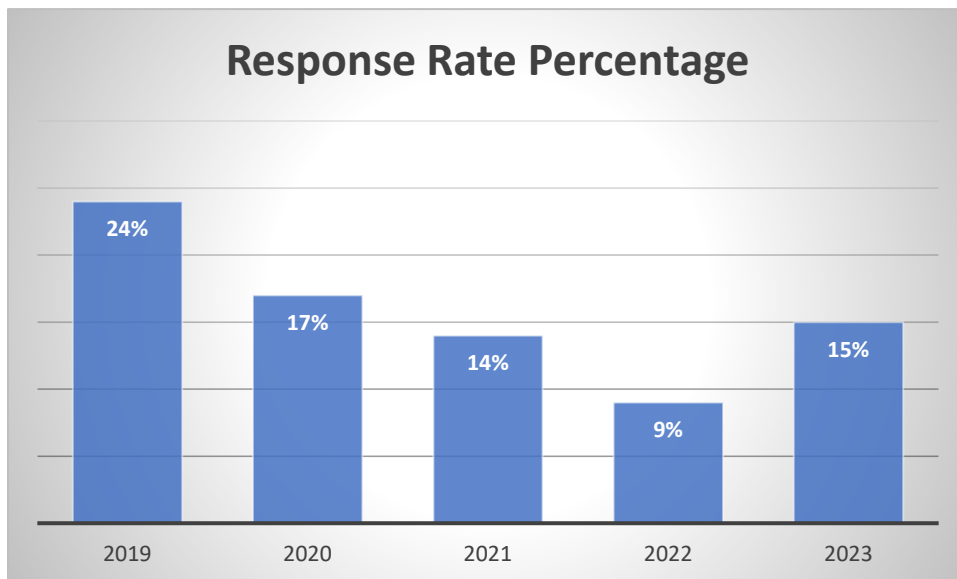


The survey consists of three sections. The Service Coordination and Program Specific sections include 13 statements which caregivers are asked to rate each statement on a 5-point scale: Strongly Disagree (1), Disagree (2), Neutral (3), Agree (4) and Strongly Agree (5). The General Comments section provides the caregiver an opportunity to share their experience in narrative form.

In January 2024, 1465 letters were mailed via the US Postal Service to caregivers with instructions on how to complete the 2203 Quality Assurance Survey. This yielded poor results, so in late January, parents/guardians received an email which included a website link and a QR Code to access the annual survey electronically. Moving forward, based on feedback from the CCOP Advisory Committee, families will receive two emails asking them to complete the annual survey electronically. In addition, we have also added a feature where families will get an email response upon survey completion confirming their submission.

For the 2023 survey, 215 surveys were received. This is the highest number of total surveys completed since 2017. **Figure B** captures the response rate from 2019-2023. This year's response rate improved since last year. The effort made to offer feedback opportunities to consumers in electronic format did increase the response rate from 9% in 2022 to 15% in 2023.

Figure B



Major Findings

Key findings and outcomes from the survey data are captured below. The Service Coordination Results and General Comments Results sections provide greater detail and analysis.

- Aggregate satisfaction with multiple dimensions of service coordinator performance remains above average and relatively stable over time.
- Service coordination and program outcomes are areas of strength, and the transition to adult services showed improvement this past year.
- Perceived self-involvement in service plan development/outcomes remains high, with 96% of caregivers endorsing “Strongly Agree” or “Agree.” (Q1)
- Average levels of satisfaction with service coordination have decreased by one or two tenths of a point, however all of the response rates for each of these questions remain above the “Agree” rating:
 - (Q2) In terms of providing useful feedback, information, and resources.
 - (Q3) Increased understanding of the program.
 - (Q4) Timely response to requests, questions, and concerns.
 - (Q5) Follow-through with requests, questions, and concerns.
 - (Q6) Assisting with meeting the needs of the child and family.
 - (Q7) The amount of time available level of satisfaction remained the same as in the previous year.
- Most caregivers (67%) continue to agree that their service coordinator assisted with preparation for transition to adult services for their child that was 17 years old as of July 1, 2023. Survey responses (Q8) increased substantially indicating families felt more supported by the service coordinator with this transition. There was significant improvement in survey responses (Q9) since last year showing families felt more prepared for the transition to adult services.
- A total of 52 out of 1465 caregivers indicated that their child experienced severe health and/or safety concerns while waiting for services which was an increase since last year (Q10). There was improvement from 52% in 2022 to 73% in 2023 (Q10a) of responses related to caregivers being able to address their child’s needs while waiting to receive services.
- The proportion of caregivers indicating that the program served to improve overall day-to-day functioning (Q11) and to support goal achievement (Q12) remained the same as in the previous year. The response in the “Strongly Agree” and “Agree” categories increased (Q11) from 69% in 2022 to 72% in 2023 and (Q12) from 60% in 2022 to 66% in 2023.

Program and Practice Adjustments

Data gathered through the survey process is utilized for continuous quality improvement efforts. The CSN leadership team evaluates the findings and themes to formulate strategies for how to build upon strengths and address areas of concern. Below is an example of how feedback from caregivers has been incorporated into program and practice enhancements to best serve children and their families with special needs.

The CSN Program is excited to share that the “waitlist” for the CLTS Waiver ended in March of 2023. We eliminated the waitlist for enrollment into the program and have remained in continuous enrollment status since then. In order to accomplish this goal, the leadership and service coordinators worked incredibly hard to train and support a team of 58 service coordinators to serve 1,444 children in 2023. By mid-June 2024, we are projected to have approximately 1,550 youth enrolled in CLTS.

While the CSN Program is pleased to be able to service all youth enrolled with service coordination, we have seen the contracted CLTS Waiver service providers struggle to keep up with the high demand of services. As noted in Figures 16 and 17, the largest gap and concern is access to Providers and Services. In addition, (Q10) notes that many families are still experiencing a health or safety related need while they are waiting for services. To help address this concern, the CLTS program hired a full time Provider Relations Specialist Position in August of 2023 to expedite the onboarding of new CLTS Waiver service providers. The intent is to provide support to fully qualified providers regarding topics such as navigating the State's Third-Party Payment Administrator. We believe this position has already yielded positive results based on feedback received from providers. As of May of 2024, CLTS has signed contracts with ten new providers in less time it took in 2023 to onboard the same number of providers. A provider recruitment strategic plan has been developed for 2024 with a goal to onboard a minimum of 20 new service providers before year-end.

Question 9 on Page 15, states, **“My child was 17 years old as of July 1st, 2023; I feel that as a family we are prepared for the transition to adult services”**. The average response in 2022 improved to 3.2 – closest to Neutral. The average response in 2023 improved significantly to 3.8 – closest to Agree. Over the past two years, CLTS partnered with the Aging and Disability Resource Center (ADRC) to provide quarterly Youth Transition Presentations which rotate between in person and virtual attendance. These presentations provide education for the youth transition to adult services and provide access to an educational guest speaker. The ADRC also has a Transition Guide to assist families in the process. Transition resources can be found at: <https://www.waukeshacounty.gov/ADRC/>.

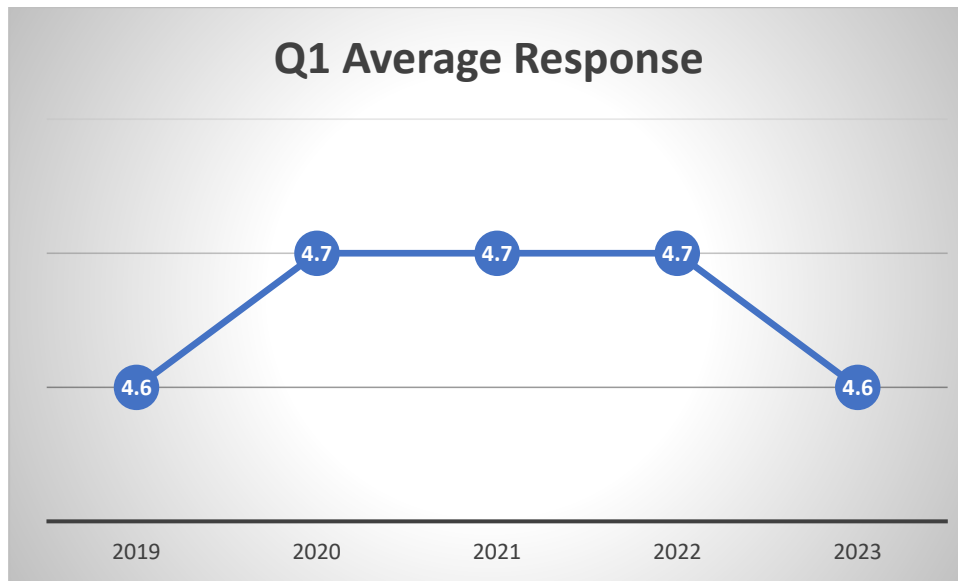
The Children with Special Needs Program is dedicated to enhancing the delivery of services to youth with special needs in Waukesha County with the goal of the best possible program experience for families. In 2024, two primary goals are to continue to expand the provider network and to stabilize the response and reimbursement timeframes for CCOP requests. CLTS is also preparing program operations to be converted to all electronic processes to eliminate paper records. This will include an updated release of information for families to sign and a review of program policies and procedures to assure alignment with Department of Health Services requirements. These efforts will create efficiencies and enable service coordinators to spend more direct time interfacing with the youth and families that they serve.

Service Coordination Results

Question 1: I am involved in the development of my child’s Individual Service Plan (ISP) and Outcomes.

Figure 1 shows that the average response (4.6) was closest to “Strongly Agree,” and this response rate has decreased slightly from the previous year. A total of 206 caregivers (96%) selected “Agree” or “Strongly Agree” in 2023.

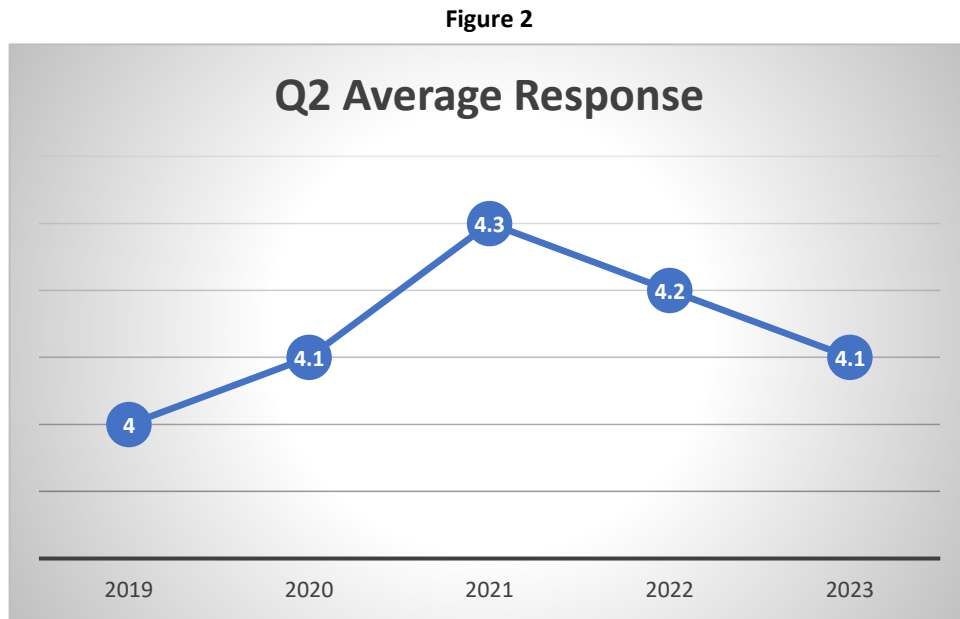
Figure 1



Q1	2019	2020	2021	2022	2023
Strongly Agree	106	86	85	72	137
Agree	31	23	24	25	69
Neutral	5	3	1	2	4
Disagree	1	0	1	1	1
Strongly Disagree	3	1	0	0	3
n=	146	113	111	100	214

Question 2: I am provided with useful feedback, information, and resources in relation to my child's needs.

Figure 2 captures that the average response (4.1) is closest to “Agree”, and this response rate has decreased slightly from the previous year. A total of 174 caregivers (81%) selected “Agree” or “Strongly Agree” in 2023.

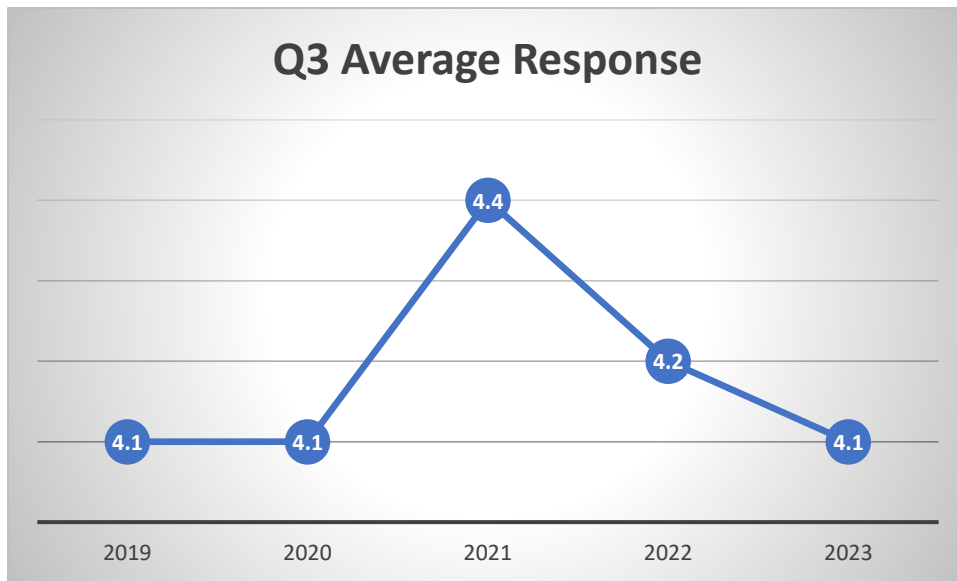


Q2	2019	2020	2021	2022	2023
Strongly Agree	63	50	60	48	93
Agree	49	39	34	34	81
Neutral	17	18	9	12	21
Disagree	11	4	7	2	9
Strongly Disagree	6	3	2	3	10
n=	146	114	112	99	214

Question 3: My service coordinator helps me to better understand the abilities and limitations for the programs that we are currently participating.

Figure 3 shows that the average response (4.1) is closest to “Agree”, and that the average level of agreement has decreased slightly from the previous year. A total of 170 caregivers (79%) selected “Agree” or “Strongly Agree” in 2023.

Figure 3

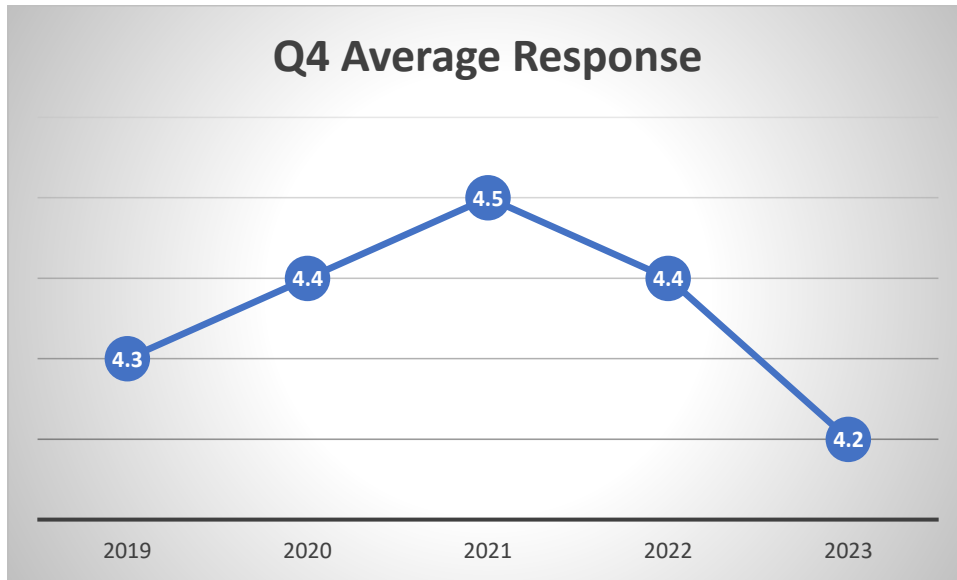


Q3	2019	2020	2021	2022	2023
Strongly Agree	68	48	68	49	98
Agree	47	47	29	34	72
Neutral	15	7	10	10	22
Disagree	5	7	4	1	10
Strongly Disagree	10	4	1	6	12
n=	145	113	112	100	214

Question 4: My requests, questions, and concerns are responded to in a timely manner.

Figure 4 shows that the average response (4.2) is closest to “Agree”, and the average level of agreement has decreased from the previous year. A total of 181 caregivers (84%) selected “Agree” or “Strongly Agree” in 2023.

Figure 4

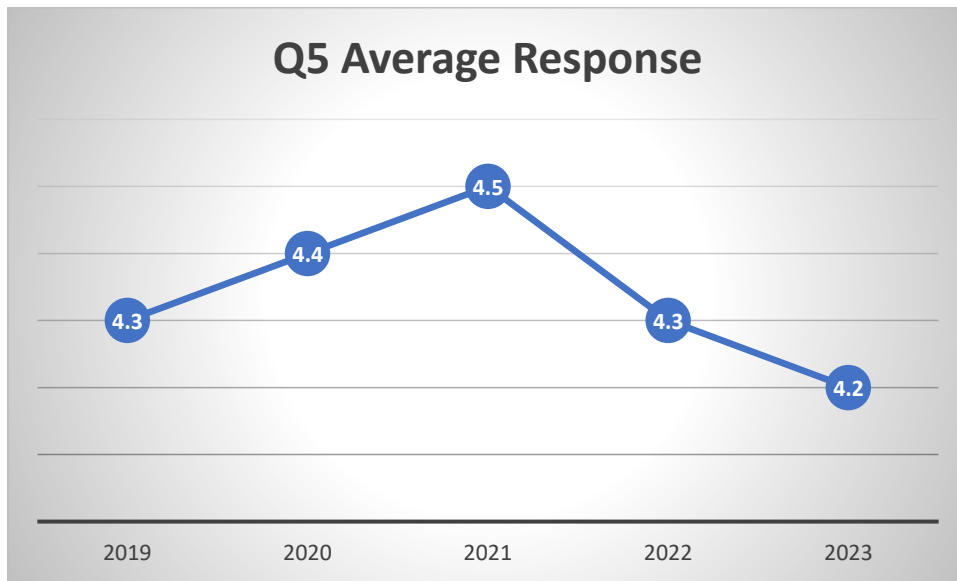


Q4	2019	2020	2021	2022	2023
Strongly Agree	82	65	71	59	111
Agree	35	35	30	28	70
Neutral	15	5	5	6	14
Disagree	9	5	2	4	12
Strongly Disagree	4	3	3	3	8
n=	145	113	111	100	215

Question 5: Follow-through to my requests, questions, and concerns are appropriate.

Figure 5 shows that the average response (4.2) is closest to “Agree”, and the average level of agreement has decreased slightly from the previous year. A total of 182 caregivers (85%) selected “Agree” or “Strongly Agree” in 2023.

Figure 5

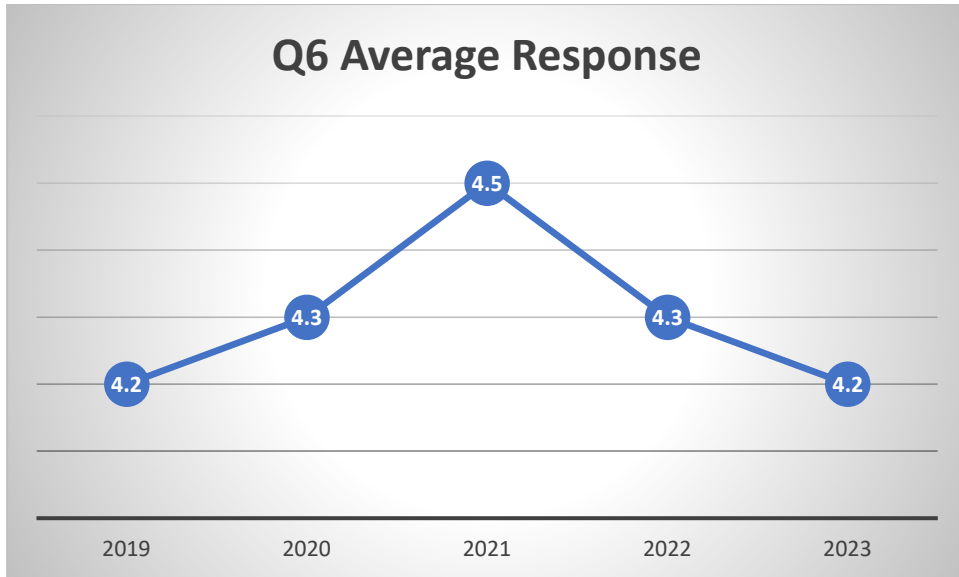


Q5	2019	2020	2021	2022	2023
Strongly Agree	78	67	68	56	104
Agree	40	30	36	28	78
Neutral	17	11	5	8	14
Disagree	6	3	0	5	10
Strongly Disagree	4	3	2	2	9
n=	145	114	111	99	215

Question 6: My service coordinator assists in meeting the needs of my child and family.

Figure 6 shows the average response (4.2) is closest to “Agree”, and the average level of agreement has decreased slightly from the previous year. A total of 181 caregivers (84%) selected “Agree” or “Strongly Agree” in 2023.

Figure 6

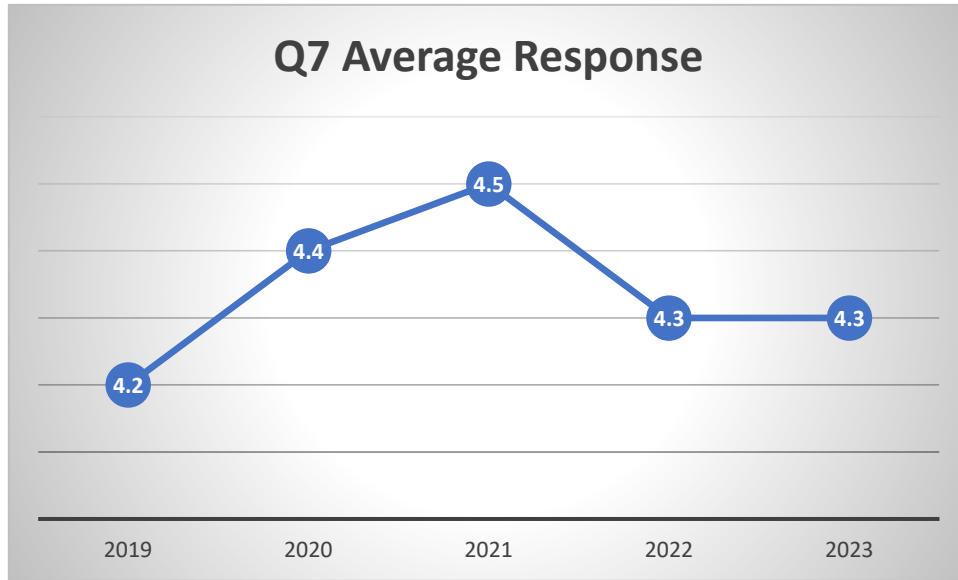


Q6	2019	2020	2021	2022	2023
Strongly Agree	72	63	68	48	107
Agree	45	36	36	40	74
Neutral	21	7	5	6	16
Disagree	4	1	0	1	6
Strongly Disagree	5	5	2	4	12
n=	147	112	111	99	215

Question 7: I am satisfied with the amount of time my service coordinator is available to my family.

Figure 7 shows that the average response (4.3) is between “Agree” and “Strongly Agree.” The average level of agreement with this statement has stayed the same from the previous year. A total of 184 caregivers (86%) selected “Agree” or “Strongly Agree” in 2023.

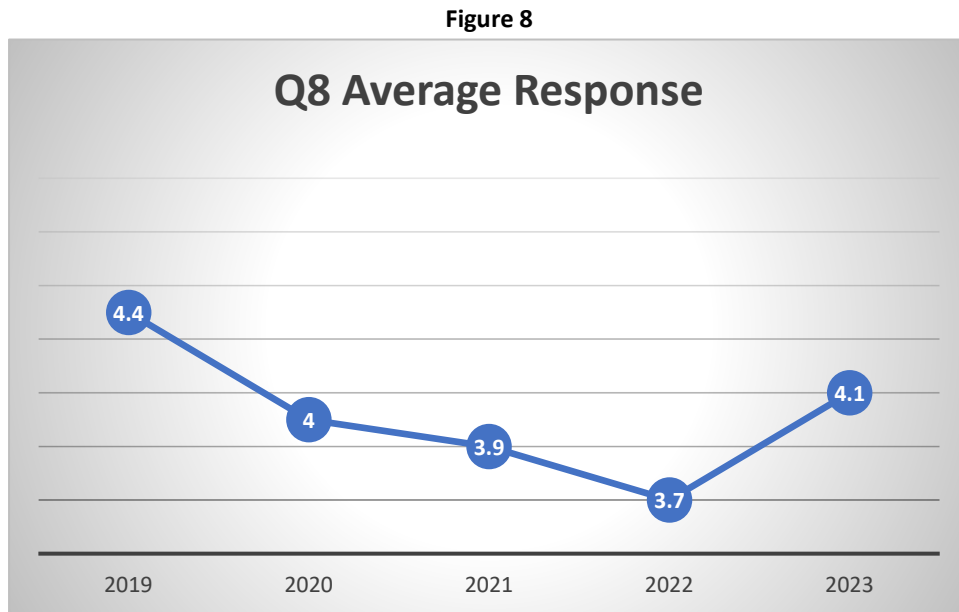
Figure 7



Q7	2019	2020	2021	2022	2023
Strongly Agree	74	67	71	50	111
Agree	48	37	30	35	73
Neutral	14	6	7	8	15
Disagree	5	1	2	5	6
Strongly Disagree	6	3	2	1	10
n=	147	114	112	99	215

Question 8:*[My child was 17 years old as of July 1st, 2023] My service coordinator has provided me assistance with the transition to adult services process.*

Figure 8 shows that the average response to this item (4.1) is closest to “Agree”, and this represents a significant increase in response from the previous year (3.7). Note the total number of caregiver responses to this question was 9 in 2023.

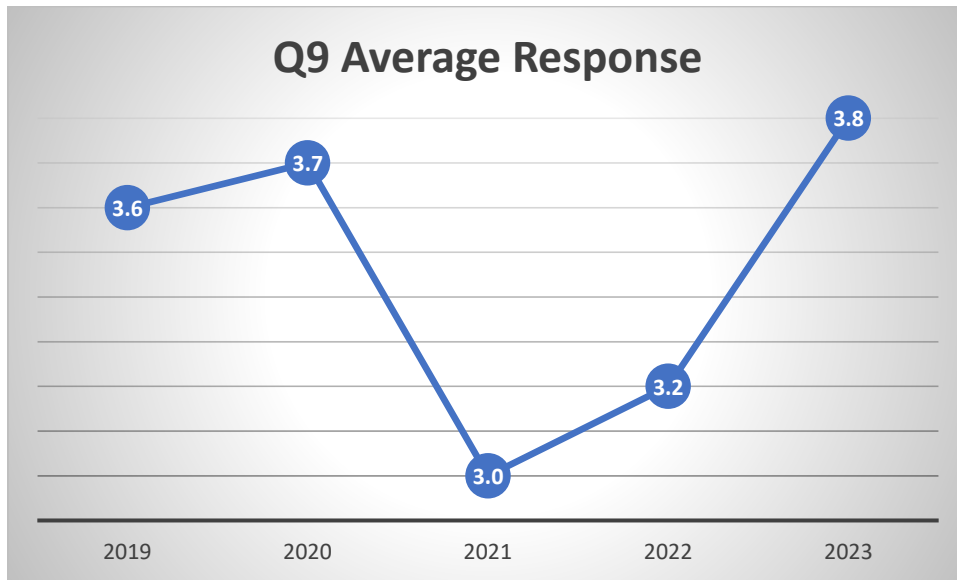


Q8	2019	2020	2021	2022	2023
Strongly Agree	4	2	6	7	6
Agree	2	1	3	4	0
Neutral	1	0	1	3	2
Disagree	0	1	0	0	0
Strongly Disagree	0	0	2	3	1
n=	7	4	12	17	9

Question 9: “[My child was 17 years old as of July 1st, 2023] I feel that as a family we are prepared for the transition to adult services.”

Figure 9 shows that the average response (3.8) is closest to “Agree”, and the average response has substantially increased since the previous year (3.2). The response in 2023 has been the highest in the past 5 years. Note that total number of caregiver responses to this question was 9 in 2023.

Figure 9

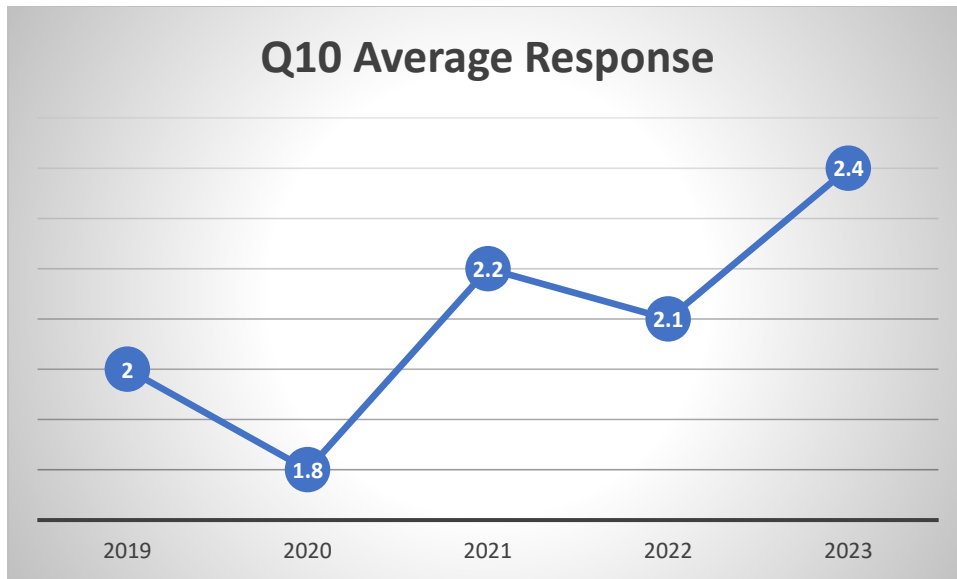


Q9	2019	2020	2021	2022	2023
Strongly Agree	3	3	1	3	2
Agree	4	2	3	2	5
Neutral	2	2	0	5	1
Disagree	1	2	1	1	0
Strongly Disagree	0	0	2	2	1
n=	10	9	7	13	9

Question 10: While waiting to receive services, my family and/or child experienced extreme health and safety concern(s).

Figure 10 shows that the average response (2.4) is between “Neutral” and “Disagree”, and the level of agreement with this statement increased since the previous year, indicating a decrease in this response. Of the 212 responses, 160 (75%) endorsed responses of “Neutral,” “Disagree” or “Strongly Disagree” which indicates their child did not experience extreme health or safety concerns while waiting for services. In 2022, 81% endorsed responses of “Neutral,” “Disagree” or “Strongly Disagree” which indicated their child did not experience extreme health or safety concerns while waiting for services.

Figure 10

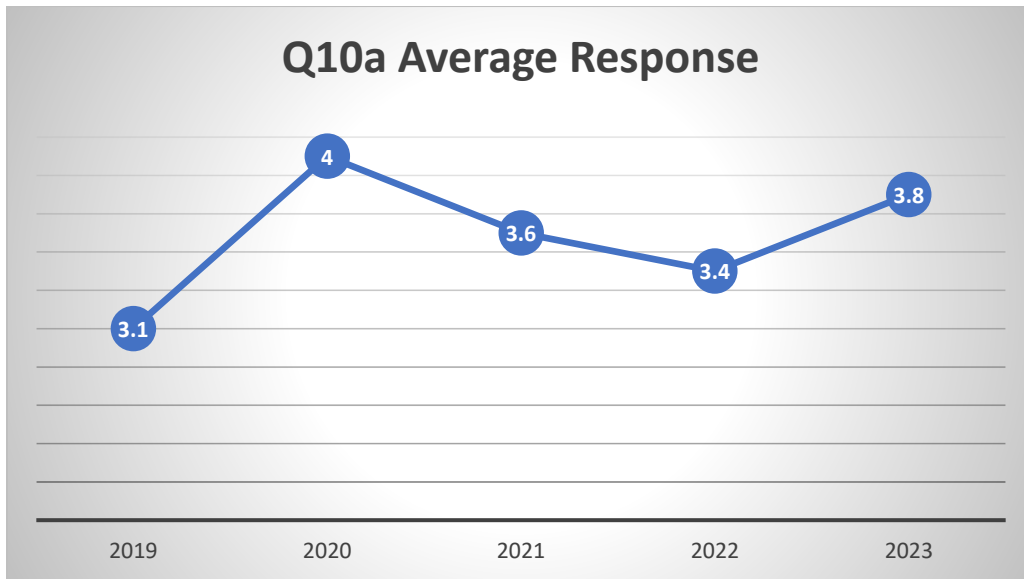


Q10	2019	2020	2021	2022	2023
Strongly Agree	10	10	10	7	18
Agree	11	2	12	10	34
Neutral	19	12	12	14	36
Disagree	29	22	19	16	57
Strongly Disagree	67	64	46	44	67
n=	136	110	99	91	212

Those who answered “Agree” or “Strongly agree” to question ten were asked to state their agreement with a follow-up statement (10a): “While waiting to receive services, my family was able to address the extreme health and safety concern(s).”

Figure 10a shows the average response to the question (3.8) is closest to “Agree.” The average level of agreement has substantially increased from the previous year (3.4) indicating improvement in the family’s ability to address any health and safety concerns while waiting to receive services. Note that total number of responses to this question was 52 in 2023.

Figure 10a

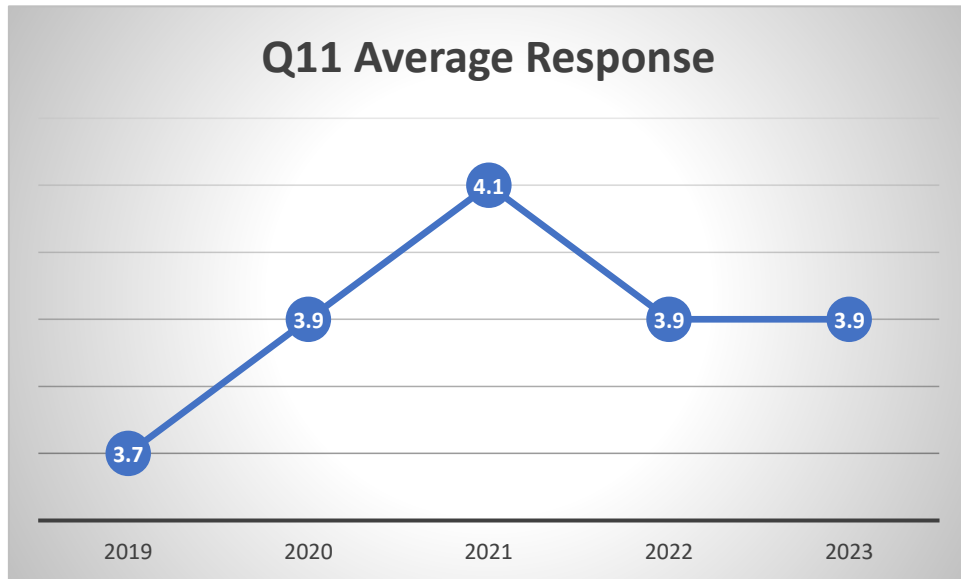


Q10a	2019	2020	2021	2022	2023
Strongly Agree	3	6	5	6	14
Agree	4	2	6	6	24
Neutral	3	2	4	5	7
Disagree	4	2	1	4	5
Strongly Disagree	2	0	2	2	2
n=	16	12	18	23	52

Question 11: My family’s overall day- to-day functioning improved after we started to receive services through these programs.

Figure 11 shows that the average response (3.9) is closest to “Agree”, and that the level of agreement with this statement stayed the same since the previous year. A total of 154 of the caregivers (72%) endorsed “Agree” or “Strongly Agree.”

Figure 11

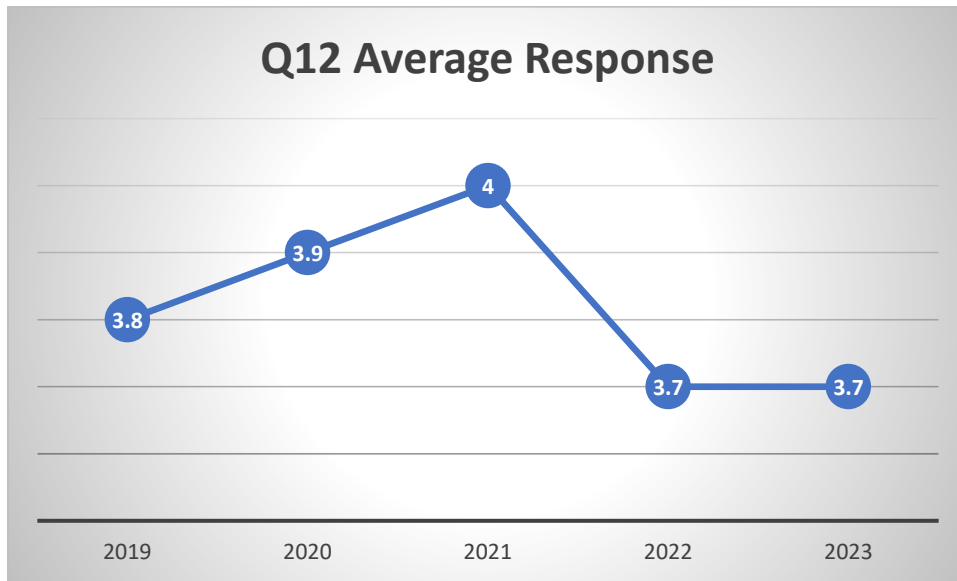


Q11	2019	2020	2021	2022	2023
Strongly Agree	46	39	42	29	69
Agree	56	42	48	37	85
Neutral	32	25	17	23	45
Disagree	7	3	2	5	7
Strongly Disagree	3	4	2	2	9
n=	144	113	111	96	215

Question 12: The goals during this year that my family established as most important were reached through involvement with these programs.

Figure 12 shows that the average response (3.7) is closest to “Agree,” and responses to this item have stayed the same since the previous year. A total of 141 of the caregivers (66%) endorsed “Agree” or “Strongly Agree.”

Figure 12



Q12	2019	2020	2021	2022	2023
Strongly Agree	41	30	32	25	48
Agree	52	50	53	33	93
Neutral	38	24	21	28	50
Disagree	7	5	2	6	13
Strongly Disagree	5	4	1	4	11
n=	143	113	109	96	215

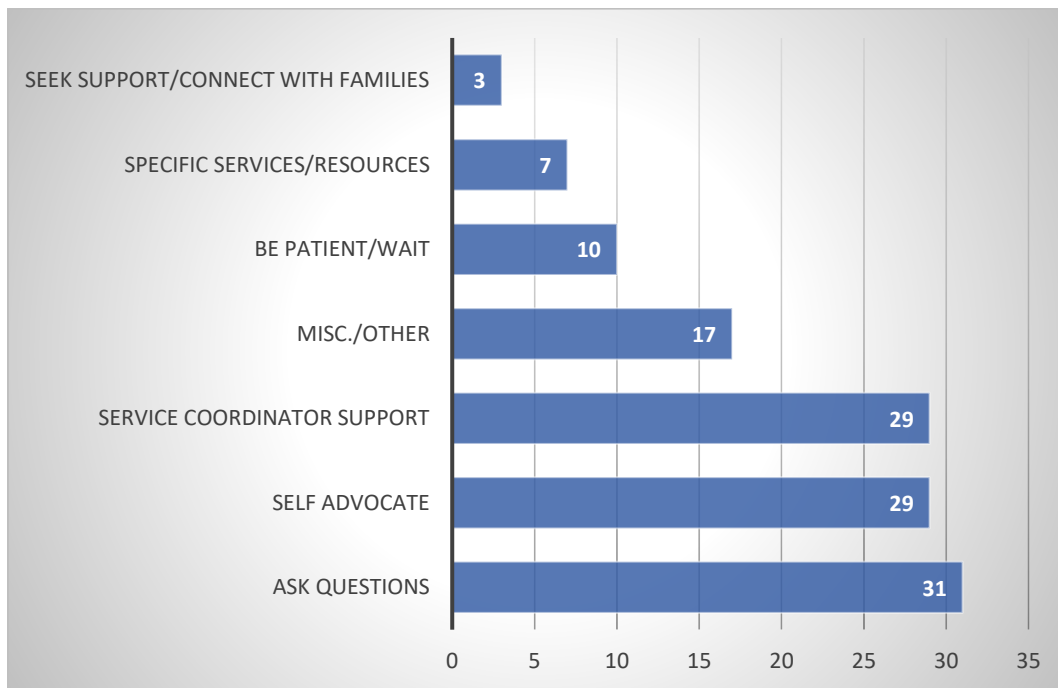
General Comment Results

In addition to rating Service Coordination statements, caregivers were also asked three open-ended questions to garner their thoughts and opinions in narrative form. For purposes of this report, responses were grouped based on common themes.

Question 1: “What type of advice would you offer to families or parents of children with special needs that are new to the program?”

Of the 215 completed surveys, 126 caregivers replied to this question, with some caregivers providing multiple responses. A full summary of all caregiver responses can be found in Appendix A. **Figure 14** captures frequency of responses based on seven theme categories. The greatest advice that respondents would give to families that are new to the program is to Ask Questions (31), Self-Advocate (29), and recognize Service Coordinator Support (29). These three themes accounted for 71% (89) of the 126 responses to this open-ended question.

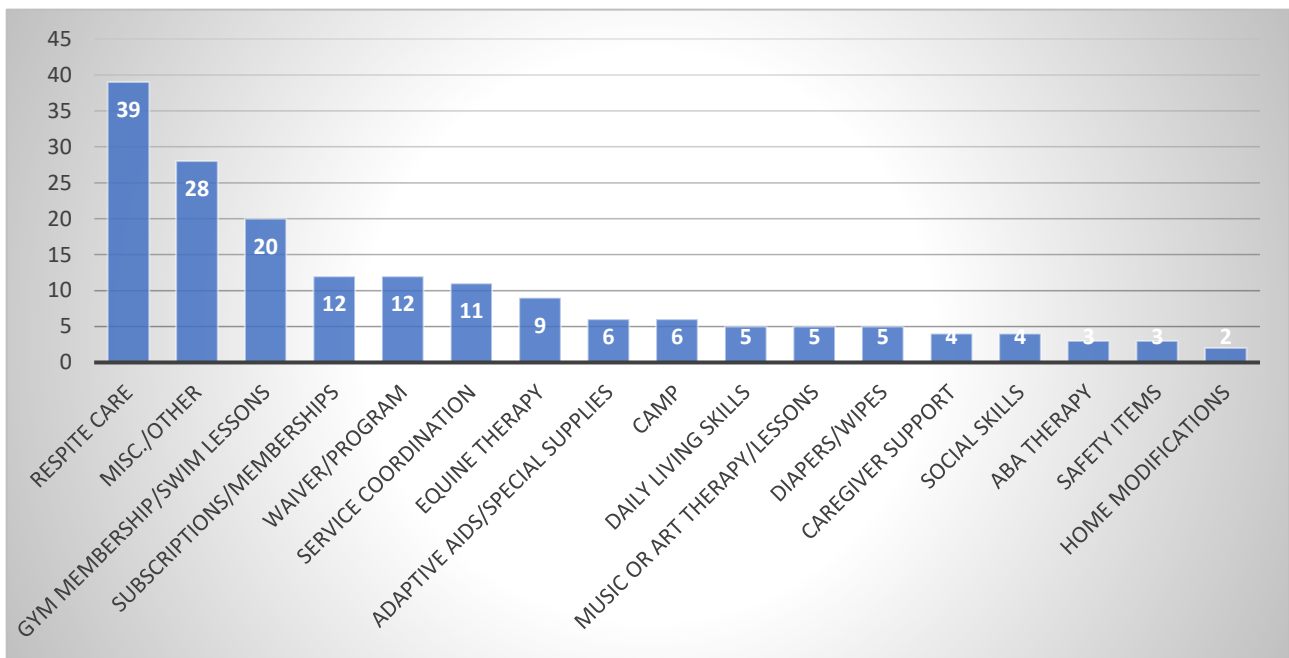
Figure 14



Question 2: What services or support were most helpful to your family?

Out of 215 completed surveys, 174 caregivers replied to this question, with some caregivers providing multiple responses. A full summary of all caregiver responses can be found in Appendix B. **Figure 15** captures frequency of responses based on seventeen theme categories. Caregivers shared that the most helpful service or support to their family was Respite Care (39) which accounted for 22% of the total responses. Positive comments were also received regarding Health and Wellness Services (20) which accounted for 12% of the total responses.

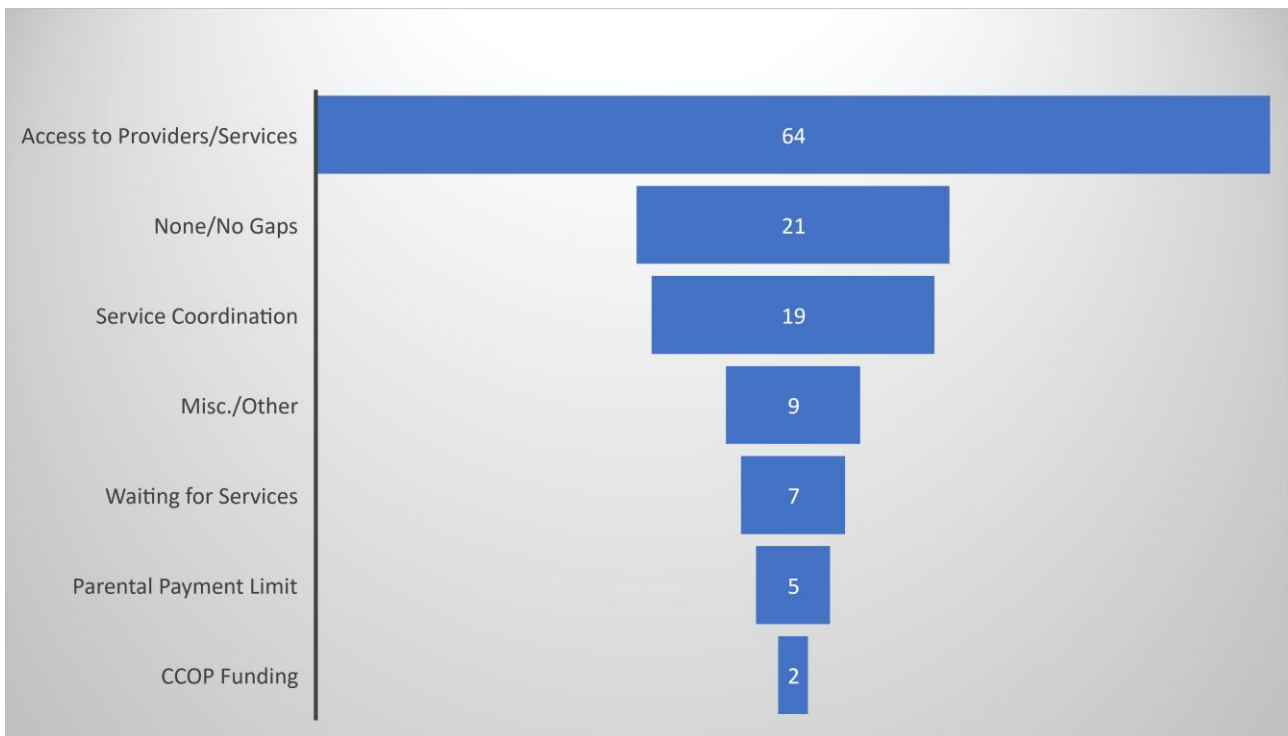
Figure 15



Question 3: Where are the gaps in services/support?

Out of 215 completed surveys, 127 caregivers replied to this question, with some caregivers providing multiple responses. A full summary of all caregiver responses can be found in Appendix C. **Figure 16** captures frequency of responses based on seven theme categories. The most prevalent gap identified by caregivers was Access to Providers/Services (64) which accounted for 50% of the total responses. An area of strength was noted in that 21 of responses (17%) indicated there are no gaps in services/support.

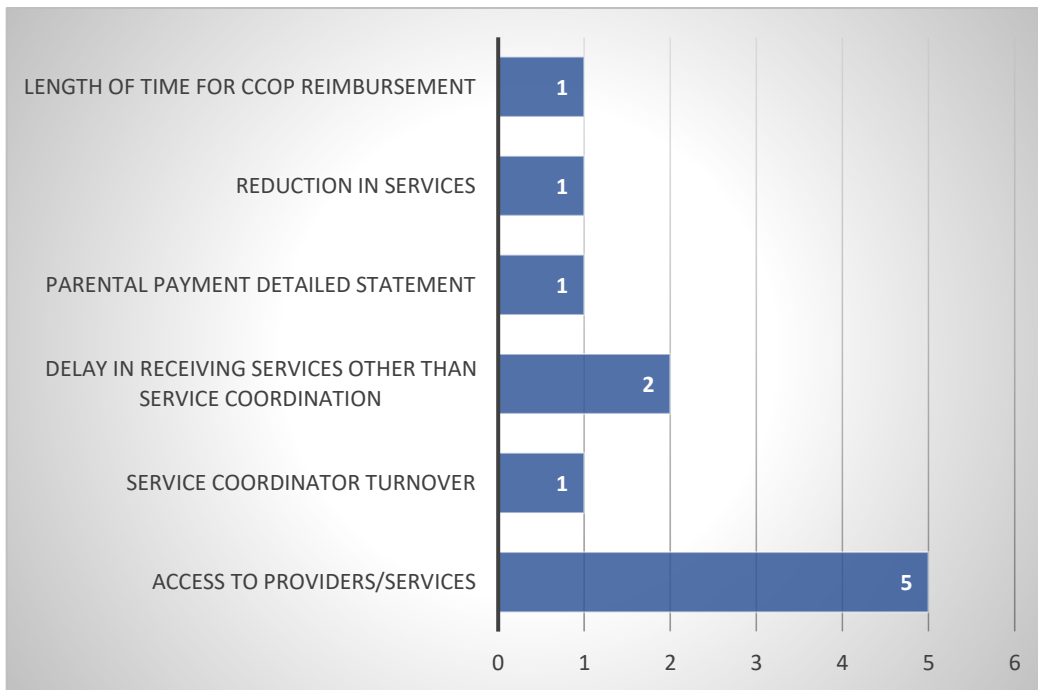
Figure 16



Question 4: I have additional questions and/or comments regarding services and I would like for a member of leadership to contact me.

Out of 215 completed surveys, 11 caregivers replied to this question, requesting contact from a member of the CSN leadership. **Figure 17** captures frequency of responses based on six theme categories. The most prevalent concern identified by caregivers was Access to Providers/Services (5) which accounted for 46% of the total responses. Another area of concern was the delay in receiving services other than Service Coordination (2) which accounted for 18% of the total responses.

Figure 17



Appendix A

Responses and grouping of general comments to *Question 1: "What type of advice would you offer to families or parents of children with special needs that are new to the program?"*

Ask Questions:

- Ask a lot of questions. The coordinators are very kind and want to help.
- Services are based off of goals set. Reach out if you have questions or concerns.
- Ask a lot of questions and really dig deep on. What services are really available since new coordinators sometimes struggle with that. Waukesha county has a plethora of opportunities so again...Just make sure that you are aware of what they are.
- Be patient with the process and reach out to coordinator as often as needed, you are not alone! Ask as many questions as possible!
- Advocate for your child and don't be afraid to ask as many questions as you need.
- Do your homework about all the services available to you. Ask questions and lean into those who are there to offer you a helping hand.
- Always asked questions.
- Gain as much information as possible.
- If you don't understand something just ask! Don't make any assumptions! You have to receive approval; for something before you register.
- Ask for help. Be honest.
- Take the time to ask questions. The coordinators do this stuff all the time so often they have an idea or advice to share. Also ask about anything. The worst thing I've ever been told is no, but at least I know.
- Spend the time understanding what you can ask for from the Waiver program. Or just ask. You never know!
- Try your best to get information on what is covered and not. It's been hard to know what to ask for. Sometimes a service is supported, and then the same service or one very similar is not.
- Just ask.
- Be thorough in your requests; explain why your request would benefit your child - give specific examples. Don't be afraid to ask questions or ask for anything you need; the worst they can say is no.
- Keep asking questions, bring your service coordinator to your IEP meetings, and always advocate for your child's needs!
- Ask questions about things you don't understand because there is a lot that comes in the beginning of the process.
- Ask questions and learn what you can. The is new to most of us and the staff is so helpful.
- Ask questions.
- Don't be afraid to ask questions. There are many services available, and you don't know until you ask.
- Although we are new to the program on a personal level, I would encourage families not to be afraid to ask any questions and to communicate what they really want to get out of the program. This helps the team to get a better understanding how to meet those needs and best explain what is available for services.
- Ask lots of questions.
- When in doubt, ask.
- Ask many Questions as the services are plentiful.
- Ask questions! Nothing is a dumb question.
- Don't hesitate to ask questions.
- Ask as many questions as you have.
- Ask a lot of questions, there is a lot of support available, but it can be hard to find everything available to you even with the service coordinator's assistance.
- Always ask questions, go to special needs events as you will get information from other families and a great place for families to support each other and feel accepted, part of a group.
- Ask lots of questions and make sure to share all of your challenges.
- Don't hesitate to ask. Worst case, the answer is no.

Self-Advocate:

- Don't be afraid to ask for something that may benefit your child.
- Think of goals you need your child to achieve and ask about services that would compliment and advance the need.
- Be prepared to fight for everything you need. Service coordinators will find any way to deny your requests and make things as difficult as possible.
- The parent is the best advocate. No one can do it for you.
- When we were first offered the program, we were recommended to waive services as it "didn't seem a need" at the time - don't do that! Even if you can't think of something specific right now, keeping the service active from the start is the best way to go.
- Self-advocacy and self-research as our experience with the program was our service coordinator not helping us navigate this confusing territory.
- It is a good program and many helpful services. Start early before you need services as process is lengthy for some services. You must be an active advocate for your child.
- -Advocate for your child's needs. Don't wait for your service provider to offer things, do your research.
- Set clear goals in a variety of areas of the child's development.
- Use the program. Don't be afraid to ask for help, or for things that seem greedy. There are many resources you may be able to take advantage of, but not if no one knows you need it.
- Be a strong advocate and don't be afraid to repeatedly contact your worker.
- Ask early and often for things you need. The earlier you ask the faster you get them.
- Take an active part in services.
- Be persistent. Use your voice and speak up. Follow up and don't take the quick no that you will get as the final answer.
- Be willing to take all opportunities that are presented to you so you can make an informed decision on whether they are right for your child and family.
- Research as much as you can.
- Explore as many opportunities as you can!
- Think of all aspects of your child's life when making a list of needs.
- Research what is available to you and try to determine what will be most beneficial to your child overall - considering both physical and emotional well-being.
- Don't do what others do, consider your family and your child's individual needs.
- The CLTS services and support offered to families with special needs children will change your life.
- Be sure to be very involved and read all of the documents carefully. We noticed several errors in the information from our child's intake appointment.
- Don't be afraid to ask for services or see if something is covered.
- Communication is essential. Ask questions and do your own research. If you think something might work for your child, ask. If it is not presented to you, it doesn't mean it isn't an option. You know your child best, so be the best advocate you can be. Being an advocate for your child does not mean you are being high maintenance or problematic; it means you are being a great parent.
- Do your research so you are educated.
- Make sure to utilize all the resources available to you.
- Be honest in the needs of your child. If you think a service would be helpful ask your coordinator and they will check to see if it is something that would be covered.
- I would recommend that they avail themselves of all available programs.
- Don't ask for the moon as this is a govt program with limitations. A lot of our kids growth comes from our efforts working with them and doing what we can with our resources when it is within our power. Some kiddo definitely need more support so documentation and advocacy is your best friend.

Service Coordinator Support:

- Get to know your person assigned to you. He/she is out to help you and your child be successful.
- Advocate, advocate, advocate. Our service coordinator has been less than helpful in providing information and resources. Their particular communication-style is ineffective. I believe a service coordinator should bring ideas, resources, suggestions, and examples to a family, not leave a family to do their own research and speak to others in order to determine how to get support.
- Communication with your service coordinator is extremely important.
- Hope that they will assign you with a service coordinator that care.
- Hope they assign a service coordinator who cares.
- Share your concerns and dreams with your coordinator.
- Stay in communication with your service coordinator.
- There are a lot of useful programs out there. Talk to everyone you can including your service coordinator but also therapists and other groups working with special needs.
- Talk to your coordinator, they will help you they aren't mind readers.
- Explain a typical day to your coordinator so they can understand the daily needs of your child.
- Don't expect to get what you need. Always ask for things your service coordinator knows of that will help your Child.
- Leverage your coordinator. They have many avenues to identify support resources. Don't be afraid to ask, you will be politely told if you don't qualify.
- Don't be afraid to talk to your service coordinator and ask what questions!
- Be in constant communication with your coordinator.
- Our service coordinator is very attentive and helpful.
- Work closely with your service coordinator to fully understand everything this program has to offer.
- Please take the time to talk to the program coordinator and learn how she/he can provide different support for your child. We didn't know some of the benefits available until talking to them.
- I would advise them to not be afraid to reach out with any questions or concerns they may have. I have felt nothing but support from your service coordinator, and she always responds to me in a timely manner and offers resources to try.
- Always check with your coordinator about details. If possible, request for coordinator not to be changed. We had 3 diff case workers in a 6-month frame. When the case gets transferred to a new worker it becomes challenging on both sides.
- Get involved in your child support and work together with the case manager.
- Be prepared for pronounced delays in hearing back from service coordinators.
- We just started the program and have only been in contact once with our service provider, but she seems very thorough and easy to work with.
- Talk to your coordinator as often as needed. Your coordinator can answer your questions.
- Work with the coordinator to understand how things work. There is a bit of a learning curve to go through.
- Communication with your advisor is key.
- Do your best to find the means of communication that works best for you and your coordinator and do your best to communicate diligently. It can be challenging with everything going on in life- work, house, family, other children, all the other things for your child on CLTS, etc. But good communication with your coordinator is key.
- Continue to share your family/child's story and have conversations with your service coordinator. I learned about services I didn't know were available just by sharing what our family does inside and outside the home. With so many services available, your service coordinator will be able to guide you toward services that fit your family/child's specific needs.
- Communicate well with your service coordinator and make sure you know what is available for services.
- The coordinators are very helpful and knowledgeable. We really leaned into their expertise and appreciated all the help we got!

Misc./Other:

- What a blessing to see how much HHS cares about my kids and family.
- It is challenging to find providers and there is often a delay in approval for services. It's important to anticipate this upfront.
- Get your paperwork in promptly.
- Promptly fill out paperwork.
- I just signed up and haven't actually received any services yet.
- Waukesha County CLTS Supervisor should be fired. Waukesha County CLTS should be audited by Wisconsin DHS to perform a full request & denial analysis as well as review to show how inequitable the county is for CLTS families. They cause more harm & stress than assistance to families of children with disabilities. They prioritize "cost savings" for "taxpayers" over the health & wellness assistance CLTS objective. The program is federally funded pass-through, there is zero reason for all the denials and undue stress Waukesha County provides. Any other county in the state is a better role model of CLTS than Waukesha.
- Some requirements were not explained thoroughly.
- I can't offer any advice because I feel I am still too new to the program. I find it confusing and (no fault of the coordinator) difficult to understand and navigate. Most people that I have encountered in person and on the phone or email talk to me as if I already know how it works and I feel dumb not understanding what things are available from what part of the program. It's very complicated and intimidating and the few times I've tried to get assistance it's been denied or just gone to the wayside.
- -We have received no services to date.
- Finding good resources and services is hard. Even we find an appropriate service, there a long wait list. Hope the program has more partners to provide better services in a timely manner.
- Be prepared for lots of repetitive paperwork and changing of names of things and who is in charge of them annually. It's great people working here but the bureaucracy can be very annoying.
- -I have been referred to this program by almost every community agency in Waukesha for recommendations and resources for my disabled child I have been in this program for months everything I've asked for from therapy to assisted technology to a sensory soothing swing with goals to be met has been denied with an explanation that it doesn't met a goal when he is nonverbal with a disability he also needed incontinence supplies and over the counter medication like MiraLAX and that wasn't covered no in home services like therapy that I asked for have been provided I barely get a response back from the worker and if I do it's almost two weeks out this will be my second in person meeting 1st I signed up in almost 6 months that I had to request I think everyone needs to tell the community programs that CLTS doesn't do anything for disabled kids so they can actually be able to help because there is absolutely no help not one thing have I been sent a number to call nothing when I have asked and I have emails to prove it.
- Most helpful is special needs tutoring services catered to our son's special learning needs. Also, prescription and mental health treatment were excellent and helpful.
- 1:1 therapy for my child.
- They don't know what to ask for or the timeline it takes to set up services.
- We are very grateful to the program, and it has been very helpful in giving us a direction to go because we were definitely very lost. (This comment was provided in Spanish and translated to English)
- Learn the program and what it can offer. Your SC will not help you and will rotate so often they are useless. Also GOD SPEED!

Be patient/Wait:

- Be patient and can take quite a while to be accepted into programs.
- Be patient. Sometimes things take a while.
- Be patient, request what is a priority first, advocate for your child.
- Be prepared to wait.
- Learn patience. Not only will you need it with a special needs child, but these programs are underfunded and our case managers are overworked.
- Just be patient. Once the paperwork is all done, and you are able to start getting the services it is worth the wait.
- Nothing moved fast - expect to pay out of pocket and wait months for reimbursement.
- Be patient. Take advantage of respite care to reenergize.
- Some services feel slow to come but I'm unsure if it's my coordinator or the contracted services (i.e. hippotherapy I've heard is hard to get into). Be persistent and ask for everything you think of...all they can say is no. :) It's always worth asking!
- I said neutral because we only reached around half of the goals. I will say we are making improvement even if not reaching the goal though. I would tell new families they need to be patient as things take time and make sure they prioritize. Our first concern was addressed immediately and corrected pretty quickly but gave us a huge sigh of relief. I would also tell them they have just gained a resource.

Specific Services/Resources:

- Ask questions about vendors in the area that help with respite and socialization. Those help the most to relieve stress and offer outside solutions.
- Appreciate what is offered in Waukesha County, it is excellent.
- Take the most therapies possible.
- Get the autism parent coach.
- Ask about the programs that are offered, such as contracts with the YMCA.
- Be patient. Take advantage of respite care to reenergize.
- Ask about programs before you pay for them yourself. It is hard for employees to disclose all services that are reimbursable.

Seek Support/Connect w/Other Families:

- More support for parents. Classes offered for more education on a specific subject/topic.
- Find other families in the program to help explain and give suggestions for services/programs.
- Ask for anything and everything to see if it is covered. There is not a list to review. Talk with other families on the waiver to see what they had covered.

Appendix B

Responses and grouping of general comments to **Question 2: “What services or support were most helpful to your family?”**

Respite Care:

- Respite, camp, inclusive activities, skills to build independent living skills.
- Respite and wipes for toileting and club memberships.
- Respite care.
- Respite.
- Respite and community involvement- ymca membership, camps and that type of coverage.
- Respite care was unto they took mostly all of my autistic children hours.
- Respite care was unto they took most of my autistic children hours.
- Respite.
- Respite.
- Respite Care, Horseback Riding Therapy, Zoo Pass, & YMCA Pass.
- Childcare & Respite.
- Respite services and financial assistance for big purchases like an adaptive bike.
- Respite, I was very apprehensive about using respite. In fact, I didn't use it for a long time. But my service coordinator really sat down with me and explained the benefits and now I appreciate having that time to myself, while knowing my child is with someone safe.
- Respite.
- Respite, items to help with anxiety and ADHD ordered through amazon, & equine therapy.
- Support with Daily Living Skills, Respite, Mentoring and help with our goals of Community Mobility (Driving tutoring) and Healthy Active Living (Exercise).
- Respite.
- Respite/childcare and renovations.
- Respite and wipes.
- Respite care, to make sure our child is safe, and we can get our own things done.
- The ability to get a break and know my child is cared for.
- We got a zoo pass for our family, and we have respite care.
- Social group at LifeStriders, respite when providers were available.
- Respite/childcare/ADL.
- The YMCA, as well as respite care and daily living skills payment to the people working with my child.
- Respite.
- Respite.
- Game u and respite. The camps!
- Respite care and memberships to organizations that give opportunities to our kiddo.
- Respite Care.
- Daily living skills and respite care. It would be really nice if dls/respite organizations could process payroll for more than 4 providers per pay period. We only have providers that can work a brief period at a time. Even being able to have 5 providers per paycheck would be really helpful.
- Financial assistance for respite care and an adaptive trike were most helpful.
- The respite has impacted our lives greatly. As a single mom, it gives my child a break from me, as well as myself, so I can rejuvenate and have time without him, to get groceries, cleaning, shopping for household essentials, or laundry, tasks completed without the anxiety or fear that my child may cause disruption in, which essentially takes stress off of him as well.
- Respite and Daily Living Skills funding.
- Diapers/wipes for incontinence, respite care, Zoo Pass, monthly email check-ins inquiring about how things are going, & monthly email check-ins sharing different activities in our area/community specific to our family/child's needs.

- Waiver program, respite care, Broadscope services.
- Coordinating respite. Finding a support therapist for the parents and an in-home therapist for our child.
- Respite and DLS.
- Respite services to have an in-home care provider.

Misc./Other:

- Helping us find outlets for our child to experience new things.
- Honestly just being able to talk things out with someone. ABA was extremely helpful. Opportunities for OT and speech therapy have been so important.
- The resource to ask.
- One on one services.
- FIS! This has been the best teaching and advocacy tool for my family. I feel empowered and equipped for what my daughter is in need of learning.
- When the SC offered some services that I was unaware of.
- Financial assistance for therapy programs.
- Financial support.
- We were just approved in December, so we haven't had a ton of services yet, but are excited to get our daughter in swimming lessons.
- The crisis intervention people.
- None due to Waukesha County staff denials. If it is not expressly written in the CLTS Handbook or legislation, Waukesha County will refuse to utilize their own human brains to comprehend the request and end up denying the request. CLTS Staff in Waukesha County lack creativity or innovation to truly help families. CLTS Staff treat families with disrespect & lacking dignity because they rely too heavily on their "textbook version" of intent of the program.
- Most helpful is special needs tutoring services catered to our son's special learning needs. Also prescription and mental health treatment were excellent and helpful.
- 1:1 therapy for my child.
- We are just starting in 2024.
- Haven't received any services yet. First visit was in May 2023.
- Additional financial support for therapy services not covered under our personal insurance.
- Support to help our child gain mobility freedom.
- Every service and support makes a difference for my family.
- Programs that get my child involved with others in his community.
- Sensory needs.
- It will be nice to receive some financial help with our child's programs and activities.
- I don't know if this is the right area but I am very glad for the savings we have experienced with the state insurance.
- Medical care.
- Counseling.
- The information on driving school and behind the wheel that we will be utilizing this year.
- Getting alternative therapies covered.
- The crisis intervention people.
- Sensory need support.

Gym Membership/Swim Lessons:

- Swim lessons, music therapy.
- YMCA and swim lessons.
-Respite and community involvement- YMCA membership, camps and that type of coverage.
- YMCA, swimming classes, PT resources.
- My son received a membership to the YMCA which was very beneficial to him and our family.
- Horseback Riding Therapy, Zoo Pass, & YMCA Pass.
- Respite Care, Horseback Riding Therapy, Zoo Pass, & YMCA Pass.
- YMCA membership, it was a great way for our son to strengthen muscles while doing something active as a family.
- LEARNING RX and YMCA.
- YMCA membership for my child, camp Minikani, tablet.
- YMCA helps my child burn off energy and socialize with other kids. Even if he doesn't want to play with them, he can play around them. This helps him become curious about certain things and a step closer to playing with other kids on a more consistent basis. Swimming lessons at the YMCA has been amazing as well. He loves the water and each lesson he is improving on his kicking skills.
- YMCA and horse therapy.
- The YMCA, as well as respite care and daily living skills payment to the people working with my child.
- YMCA membership & Horse therapy.
- ABA therapy swim lessons and Tae kwon do.
- YMCA membership.
- Providing financial support for programs during school breaks, YMCA membership, hygiene products, supports for adaptive stroller.
- Membership to the YMCA for swimming, getting stronger, being part of a community and knowing how to behave in locker room and public situations. Helping with attaining an adaptive bike that he is independently riding!!!
- Music therapy has been great! I'm also grateful to be starting adaptive swim.
- Therapies and athletic programs.

Subscriptions/Memberships:

- Reimbursement of the Zoo Pass.
- Learning RX and YMCA.
- We got a zoo pass for our family, and we have respite care.
- Support to help meet my son's gross motor and sensory needs both through purchasing items for our home and joining clubs out of the house.
- Membership to sensory club.
-Learning RX, timer, sack.
- We have not received any services yet.
- Game u and respite. The camps!
- Respite care and memberships to organizations that give opportunities to our kiddo.
- Diapers/wipes for incontinence, respite care, Zoo Pass, monthly email check-ins inquiring about how things are going, & monthly email check-ins sharing different activities in our area/community specific to our family/child's needs.
- Membership to the Sensory Room has been very helpful!
- Sensory club membership and music therapy.

Waiver/Program:

- None. We have limited requests, and many were denied yet are regularly approved in Milwaukee County.
- Waiver for equipment.
- All.
- Julie with Grace Commission.
- All services and support are important and helpful.

- All were.
- We have been denied by our insurance critical equipment to help my family care for my daughter and the waiver program helped purchase it for us. Without this program, I honestly wouldn't be able to provide so many things for my daughter and make caring for her easier. Thank you for everything you all do. Keep up the great work.
- The Amazon wish list through CLTS waiver.
- Waiver program, respite care, Broadscope services.
- All.
- None nothing was provided I asked about in home therapy art therapy speech therapy respite care products Medicare doesn't cover have provided nothing in over 6 months possibly 4/5 emails including mine waste of time and money this program another neighboring county has a better support system for disabled kids then Waukesha.
- Teamwork of agencies.

Service Coordinator:

- Our case manager is very nice and responsive.
- I am still waiting to figure this out. I don't feel we have been able to access the full complement of services and support due to lack of communication with the service coordinator.
- Communication with coordinator. Yoga therapy and lawyer to help with IEP.
- Meeting with psychiatrist and trauma specialist. Also having a consistent coordinator that my child got along with that works to help us find help where we didn't know there was. We love our coordinator. Stephanie has been extremely helpful and is always looking for the best match for your child when assigning people to us.
- Our service coordinator support and check-in and help getting our child the services needed.
- The service coordinators we have are pleasant and I know its not their fault it takes ridiculously long to get services started. The service coordinators have been fine to work with. Just not impressed with the wait times.
- The most helpful support has been that our coordinator told us about services that we were not aware of (e.g., Top Soccer is a free soccer practice for children with special needs).
- I am most appreciative of the knowledge base our service coordinator can bring to the table. Since day one of being able to work with CLTS, each coordinator we've had has helped me to feel a huge relief of not carrying the task alone of researching for needed activities, finding the right programs, working to obtain access, etc. With CLTS I am confident that piece of the puzzle for my child is now done at a stellar level, better than I could ever do alone.
- Diapers/wipes for incontinence, respite care, Zoo Pass, monthly email check-ins inquiring about how things are going, & monthly email check-ins sharing different activities in our area/community specific to our family/child's needs.
- Just having someone who cares about our child. That we can ? is there a service to help us with a problem or concern. If she doesn't know she always gets back to in a timely manner. Knowing we have someone like that in our corner is very calming to us.
- Talking with the caseworker to get ideas from her that are within approved limits.

Equine Therapy:

- Equine therapy and help with getting the special bicycle.
- Horseback Riding Therapy, Zoo Pass, & YMCA Pass.
- Respite Care, Horseback Riding Therapy, Zoo Pass, & YMCA Pass.
- Support with diapers, horse therapy, and hire a babysitter for a few hours.
- Respite, items to help with anxiety and ADHD ordered through amazon, & equine therapy.
- YMCA and horse therapy.
- Lifestriders therapeutic riding/OT.
- YMCA membership & Horse therapy.
- All helped. Especially therapeutic riding.

Adaptive Aids/Special Supplies:

- Indoor swings.
- Respite services and financial assistance for big purchases like an adaptive bike.
- Financial assistance for respite care and an adaptive trike were most helpful.
- We have been denied by our insurance critical equipment to help my family care for my daughter and the waiver program helped purchase it for us. Without this program, I honestly wouldn't be able to provide so many things for my daughter and make caring for her easier. Thank you for everything you all do. Keep up the great work.
- Membership to the YMCA for swimming, getting stronger, being part of a community and knowing how to behave in locker room and public situations. Helping with attaining an adaptive bike that he is independently riding!!!
- So far, we have not found any that were of extreme help. We do appreciate the ability to have items purchased off of amazon for emotional support though.

Camp:

- Respite, camp, inclusive activities, skills to build independent living skills.
- YMCA and summer camp reimbursement were the most helpful last year.
- YMCA membership for my child, camp Minikani, tablet.
- Music Therapy has been very beneficial to help my son with his expressive language and social skills. Camps are fantastic too! My son loves going to Bobcat camp where he is with peers similar to him and staff that is trained to understand kids on the spectrum.
- Game u and respite. The camps!
- Camps & Recreational activities.

Daily Living Skills:

- Support with Daily Living Skills, Respite, Mentoring and help with our goals of Community Mobility (Driving tutoring) and Healthy Active Living (Exercise).
- The YMCA, as well as respite care and daily living skills payment to the people working with my child.
- Daily living skills and respite care. It would be really nice if dls/respite organizations could process payroll for more than 4 providers per pay period. We only have providers that can work a brief period at a time. Even being able to have 5 providers per paycheck would be really helpful.
- Respite and Daily Living Skills funding.
- Respite and DLS.

Music & Art Therapy/Lessons:

- Swim lessons, music therapy.
- Art Therapy.
- Music Therapy has been very beneficial to help my son with his expressive language and social skills. Camps are fantastic too! My son loves going to Bobcat camp where he is with peers similar to him and staff that is trained to understand kids on the spectrum.
- Sensory club membership and music therapy.
- Music therapy has been great! I'm also grateful to be starting adaptive swim.

Diapers/Wipes:

- Respite and wipes for toileting and club memberships.
- Wipes and Forward Health acceptance.
- Providing financial support for programs during school breaks, YMCA membership, hygiene products, supports for adaptive stroller.
- Diapers/wipes for incontinence, respite care, Zoo Pass, monthly email check-ins inquiring about how things are going, & monthly email check-ins sharing different activities in our area/community specific to our family/child's needs.
- Being able to source things like diapers, wipes, safety devices, programs.

Caregiver Support:

- Create Behavior Solutions therapy for parents.
- Caregiver support services were the most helpful to our family.
- Community/ self-empowerment activities like Islands of Brilliance.
- One on one caregiver support for goals.

Social Skills:

- Social skills groups & Martial arts classes.
- Social group at LifeStriders, respite when providers were available.
- Help with support for social skills classes.
- Social skills class has helped our son the most.

Applied Behavior Analysis (ABA) Therapy:

- I previously found ABA services to be the most helpful but we can no longer access due to my son's age. Now, we can't find even respite workers. So frustrating.
- ABA therapy swim lessons and Tae kwon do.
- ABA and post intensive therapy.

Safety Items:

- The AngelSense watch.
- Being able to source things like diapers, wipes, safety devices, programs.
- Making sure we addressed safety. In our case our son was opening a second floor window and throwing small objects like Legos out. We couldn't nail the window shut and all bedrooms are on the second floor. We were able to get a window alarm that alerted us when he opened it once and was loud enough that he hasn't done it since. We weren't worried about the Legos as he was only throwing them in the grass rather we were worried he would try to jump out it. This allows us to actually sleep instead of worrying about sounds we hear at night thinking it may be the window.

Home Modifications:

- Home modifications - in progress.
- Respite/childcare and renovations.

Appendix C

Responses and grouping of general comments in response to **Question 3: "What are the gaps in services/supports?"**

Access to Providers/Services:

- My child wanted theater classes and those aren't covered, but it's a great opportunity for him to learn social skills and be with typical children. I wish there was a directory of services.
- Respite providers being available and the delay for CLTS to approve services at the beginning of the year. We waited the entire first quarter of the year for them to approve any services due to them stating they needed to renew provider contracts. This led to a delay in services for the child. We also did not receive any CCOP funding reimbursement until 4th quarter. This can lead to a delay in services for a child or a child not receiving the service.
- Family care - need more assistance to help those who care for the child with special needs.
- Hourly rates. Other services
- Swimming lessons at small swimming schools- swimtastics/gold fish.... They are better equipment to teach and the environment is better for our kids(not a gym). There was NO staff to accommodate us at the ymca or was so I pay for the lessons since COPP only covers a small amount. This is a social, safety and therapy experience for children. I am a lifeguard and 1st responder so I understand the importance of this for children in the autism community given the high rates of death by drowning.
- Would like more help in finding resources for ABA and how they work.
- I would like to learn about more opportunities for my child.
- We desperately need a ramp for my daughter to safely enter and leave the house.
- We need a ramp on our house to safely let my daughter enter and leave safely.
- Funding and service. Every request we submitted was denied and the explanation given regularly cited the lack of funding due to conservative leadership in the county. In addition, our experience with our service coordinator was disappointing. No one helped us to navigate this new territory.
- It's Jan 12 and I have no clue if one of our main providers will be covered for 2024.
- Difficulty getting massage therapy approved and clear explanation or path forward to approval. 6 months and still trying to understand process. Despite doing legwork myself and verifying therapist approved for other clients and sharing information with my child's coordinator.
- Cost share. We do not get any kind of breakdown for what we are sharing the cost of. I asked for an itemized bill and only received dates with a bunch of codes. There really is no way for me to reconcile the costs we are charged. Respite service is wonderful, but the administrative costs are too high. The monthly administrative fees are usually higher than the cost of respite services we use.
- Income for main caregivers is a gap. Which trickles down to housing and transportation costs. If we can pay parents of complex medical children during Covid - why not all the time?
- Honestly, it is with my older son who struggles in many ways but doesn't have a diagnosis and/or services available to help him.
- Caregivers are not getting paid fast enough as county contracts are not complete in the appropriate amount of time. The entire month of Jan. is nearly past without resolve and my workers need to be paid. All families that have PPL that needs to be paid receive a standard bill to pay without really knowing what they are paying for. The system should be set up so that the families are aware what is being provided what is the county share and what is the parent share much like one would pay their medical bills and receive and explanation of benefits where the service is broken down. This has to change. I have asked for a breakdown in the past and the info. supplied is what the fiscal Dept at the county uses but it is not user friendly or easy to read and apply. This could truly be improved upon.
- There are so many items and services that should be covered per the manual, but every time we ask for things, the SC just lists 10 obstacles to jump before they can be covered. It is exhausting. Respite is the only thing we've been able to get in the past few years. Also, our CS takes at least a week to respond and then, even if I respond to her immediately, she takes another week to respond to that. By the time we finish a conversation about a request, weeks have gone by.

- More clarity of services needed. A menu of things covered would be helpful. Family services through memberships. I am unable to leave other children at home in order to take my child to such places as the YMCA or sensory gym.
- Qualified providers for respite and childcare- zero accountability and no support for training.
- Options For older children.
- Finding respite providers in close proximity that are willing to work for short period at a time. It's hard to find, as most people don't want to break up their whole day for just a few hours.
- Identifying opportunities for transition from school to workforce.
- Still waiting for life striders social group.
- I would like my child to get stronger while also learning how to swim. This is an essential life skill.
- Finding a therapist that is able to meet at night, so we don't have to pull our child from school. They miss enough school on their own so we wish not to add to it. Would love to see more evening appointments available to accommodate families where parents work.
- It is sometimes difficult to get approval for medically necessary items that are not covered by insurance.
- Having the info for requirements.
- No one was able to help us find psychiatric in-patient help for our daughter who has medical and psychiatric needs. Such a facility does not exist in the state of WI, so we were left to handle this difficult chapter with her on our own, which lasted months. As her parents, we were being physically, emotionally, and mentally hurt by our daughter with no help. This is a gap.
- Respite due to lack of providers.
- There was a waiting period to meet with our child's psychiatrist that was not related to your program. Mental health industry needs faster support for children as the sooner they received support the better they grow up.
- Summer camps for my child and his brother closer to home. Availability to sensory equipment that is not through Amazon.
- We could use programs that support kids 13 plus who are aging out of schools out day camps but are unable to be home alone.
- Recommendations on resources that would be good for my son.
- Assistance in paying for Waukesha community programs like the Waukesha YMCA Dance Classes, Donna Lexa Art Therapy, Waukesha Civic Theater involvement.
- Services are approved but there are no providers available to provide service. Super frustrating.
- When a service is not immediately available.
- When signing up for services, we were asked if we wanted services to be retroactive a few months. Even though we were approved going back a few months, financial approval was only granted for the present month approved, so that it didn't seem to make any difference in requesting retroactive services.
- OT services.
- Unfortunately, just not having enough staff to be able to start services sooner. I was on the waiting list for almost a year before I was able to start getting help for my family.
- Wait lists are long at some places and few reasonable backups are available. A comprehensive guide to what we can/can't do.
- No CLEAR idea or LIST of services available. That makes it very difficult for new folks (and Ongoing clients) to know what services may fit their needs.
- I believe there is a lack of funding, we have been told there are no available funds for services we thought were part of the program. This is why we left the program last year. We rejoined this year for assistance with summer care, as no child care will accept our child, they do not have the staff.
- Although our support coordinator recommended providers (e.g., ABA therapy), the providers often have no vacancy or have long waiting lists.
- Demands and supplies. For my kids, we are waiting for music therapy, equine therapy. more than one and half years....
- Daycare/respite.
- The support and services are extensive. No gaps for the outcomes we are trying to achieve.

- I don't like how only one service is available per goal. Especially when no other services are currently in place for other goals.
- We have been signed up for a couple services in Washington County, and I have been curious why there is not more available in our own county. However, the types of things we were doing are not prolific activities. I assumed they were only available there and appreciated being able to access them, regardless of being far away.
- I am not happy with services this past year. We received a new coordinator in 2022, who then was on maternity leave, then came back and quit a few months later. She did not follow through with info she was going to send us, we lost our YMCA benefit as she did not follow through with getting info in on time and then did not prepare the person who took over for her to handle this. The new coordinator has now responded very slowly to my request as to this matter. It still has not been resolved and we have not been able to use the YMCA (family respite and son takes private swim lessons) since November. No response on when it will be reinstated. I am not happy with our services at this time.
- There are not enough services available for High Functioning Autism.
- The changing of names of services and who your contact person is for specific service (Katie Beckett vs long term support waiver vs forward health vs Medicaid program).
- Hoping the pacifiers that my son uses for regulation will be approved.
- There is no help they don't do anything not even reply half the time my sons name is XXXX and you can look it up and see he has multiple needs and I have gotten nothing provided I asked for goal related devices medication therapy and she said no it's the parents job to provide these things and that's it she barley gets back to me I had to request a meeting because I feel like I'm getting nowhere and the way the community explains the program they got it all wrong clts doesn't cover anything.
- The gap between services with the YMCA membership was a little frustrating.
- We need to travel out of town to find a kid's dentist who accepts Medicaid.
- Availability of services, bobcat camp, lack of follow up with service providers.
- Finding afterschool care during the school week or for specific days like no school for students due to staff development. Perhaps sensory needs/connecting with a therapists to provide supports for child.
- There is always difficulty finding appropriate caregivers.
- Funding or coverage for swimming lessons, specifically through Swimtastic.
- OTC medicine- melatonin not covered by insurance, costs \$50/month, reimbursement vs waiting for service coordinator to place order for requested sensory items.
- Limited coverage on activities and memberships.
- We have asked about adding swim and have not been given an answer as to if he can get help with it. We are very worried as he doesn't know how to swim.
- Some "age appropriate items". Because Amazon has items listed with appropriate ages, we were denied even though it would be beneficial. It was understood we just hope that in future the need of an item isn't solely based on age but rather how it may help the child.

None/No Gaps:

- None.
- No.
- No.
- None so far.
- Nothing to add.
- None.
- N/A.
- N/A.
- None so far.
- None currently.
- N/A.
- None.

- N/A.
- No.
- N/A
- Nope.
- None that I can think of.
- None. New case worker transitions were smooth.
- N/A
- N/A.
- n/a.

Service Coordination:

- Lack of communication outside of the required check in. We haven't been able to benefit from this program yet. It's a waste.
- Just a lot of information to be given that I don't always understand, and changes that are made each year that aren't always known right away. My case worker is great on her communication though and answers my questions thoroughly and quickly.
- Communication by the service coordinator - VERY POOR.
- Lack of communication. Given them the service coordinator the right to choose what get approved and what doesn't. Letting them choose how many respite hours you can have.
- Lack of communication . Given service coordinator the right to what get approved and what doesn't letting them choose how many hours you can have.
- Processing requests. Constant changes in case workers. No follow up with case worker on processing through the state.
- Funding and service. Every request we submitted was denied and the explanation given regularly cited the lack of funding due to conservative leadership in the county. In addition, our experience with our service coordinator was disappointing. No one helped us to navigate this new territory.
- Difficulty getting massage therapy approved and clear explanation or path forward to approval. 6 months and still trying to understand process. Despite doing legwork myself and verifying therapist approved for other clients and sharing information with my child's coordinator.
- Sometimes I wish that my service provider would be a bit more timely. Sometimes it takes a week or 2 to have a question answered. I wish there were more services for my other child and for my husband and I to get support or learn more about ways we can help.
- There are so many items and services that should be covered per the manual, but every time we ask for things, the SC just lists 10 obstacles to jump before they can be covered. It is exhausting. Respite is the only thing we've been able to get in the past few years. Also, our CS takes at least a week to respond and hen, even if I respond to her immediately, she takes another week to respond to that. By the time we finish a conversation about a request, weeks have gone by.
- Coordinators need to be more aware of community resources.
- Lack of response from worker. Lack of info when requested ideas of services for my child.
- Every time we get transferred to another social worker it puts us back. Too much turnover. 4 social workers in 4 yrs. is obscene.
- Lack of communication outside of the required check in. We haven't been able to benefit from this program yet. It's a waste.
- Just a lot of information to be given that I don't always understand, and changes that are made each year that aren't always known right away. My case worker is great on her communication though and answers my questions thoroughly and quickly.
- Service Coordinator is beautiful.
- I feel like our child's service coordinator is more interested in telling us what CLTS can't cover and the organizations it's no affiliated with than trying to figure out how to cover the services or add an organization that aligns with our child's goals. It's frustrating to discuss something in a meeting, follow that process and then have something denied because of a technicality of how the request was submitted versus the coordinator trying to be our child's advocate and work with/inform us if there are changes in the process. It's

almost like we're begging/fighting for things to be covered that clearly align with her goals and were previously discussed.

- I am not happy with services this past year. We received a new coordinator in 2022, who then was on maternity leave, then came back and quit a few months later. She did not follow through with info she was going to send us, we lost our YMCA benefit as she did not follow through with getting info in on time and then did not prepare the person who took over for her to handle this. The new coordinator has now responded very slowly to my request as to this matter. It still has not been resolved and we have not been able to use the YMCA (family respite and son takes private swim lessons) since November. No response on when it will be reinstated. I am not happy with our services at this time.
- SC and supervisors rotate so often that they are of no assistance. This game is called the parent and the child against the world. As of the last year, it seems to take things away and save CTLS money VS getting what my son needs. AAHHH BBOOO CTLS. BOO!
- Workers are passionate, professional, and very personable.
- High staff turnover.

Misc./Other:

- It would be helpful to have a hand book for what could be approved vs not. Or have the service provider get to know the families better. In 6 months, we are on our third provider. In addition, it would be helpful to have someone help navigate the Medicaid system.
- The respite program is way too complicated. I am not utilizing it now because my caregiver would never be able to understand the computer aspect of the paperwork.
- Haven't received any services.
- Yes, several.
- I have no idea.
- The entire program is a gap in comparison to the remainder of Wisconsin. Waukesha County Supervisor makes all decisions subjectively and unfairly for the entire county. Caseworkers are not making any decisions independently. Too many caseworkers were hired in the last few years as they are not needed since they only work on a written script, which is a waste of taxpayer dollars. Providers are not contracted efficiently. Waukesha County lacks technology to operate efficiently and cost-effectively for the CLTS Program. Caseworkers are not necessary when Wisconsin can pull in a WISEID and medical records to easily determine "functionality" of a child, human intervention is not required. Waukesha County requires the use of fiscal agents, which means families are "charged" extra monthly fees for "agents" who do absolutely nothing and Waukesha County could manage the financials in a cost-effective manner through use of their own HR payroll software with simple coding of "providers." Waukesha County CLTS staff lacks real-world, current education or experience to comprehend needs for a child to live within the home, learn independence, and be fully included within the community in a realistic manner. Waukesha County places blame on lack of legislative phrasing rather than using their own human brains they're paid to use in order to comprehend INTENT of CLTS Program and IMPLEMENTING in a real-world setting. The entire CLTS Program managed by Waukesha County needs a Civil Rights Audit for recommendations on real-world implementation of supports in addition to a third-party, non-government audit for cost-saving efficiencies.
- Understanding that the needs and complexities of each neurodivergent child will vary, there can't be a standard for all of them.
- It is unfortunate that we are able to get funding for my child in some cases but not family passes for events and such. Understandably so though.
- Doing a good job.

Waiting for Services:

- Respite providers being available and the delay for CLTS to approve services at the beginning of the year. We waited the entire first quarter of the year for them to approve any services due to them stating they needed to renew provider contracts. This led to a delay in services for the child. We also did not receive any CCOP funding.
- It's Jan 12 and I have no clue if one of our main providers will be covered for 2024.
- It takes FOREVER to get into the program. So far we have had to wait 6 months to get service for our son.
- The length of time to get some services started.
- Time delay in getting service approved; misunderstanding of what was needed and if it could be provided - I spent no less than 40 hrs. on the phone between the county office and our insurance.
- It took a while to get up and running. No gaps today.
- The length of time it takes is sometimes long.

Parental Payment Limit:

- The only gap we encountered was the billing - it took a long time to get our first bill and by that time the balance had gotten rather high. It also took a long time to get the CCOPS reimbursement.
- Cost share. We do not get any kind of breakdown for what we are sharing the cost of. I asked for an itemized bill and only received dates with a bunch of codes. There really is no way for me to reconcile the costs we are charged. Respite service is wonderful, but the administrative costs are too high. The monthly administrative fees are usually higher than the cost of respite services we use.
- Caregivers are not getting paid fast enough as county contracts are not complete in the appropriate amount of time. The entire month of Jan. is nearly past without resolve and my workers need to be paid. All families that have PPL that needs to be paid receive a standard bill to pay without really knowing what they are paying for. The system should be set up so that the families are aware what is being provided what is the county share and what is the parent share much like one would pay their medical bills and receive an explanation of benefits where the service is broken down. This has to change. I have asked for a breakdown in the past and the info. supplied is what the fiscal Dept at the county uses but it is not user friendly or easy to read and apply. This could truly be improved upon.
- It would be nice if the parental payment amount based on income was evaluated again based on current cost of living. We have experienced a lot of inflation in groceries, housing, utilities, etc. in recent years.
- There is no explanation to the monthly cost share bills. There should be an itemization but there isn't. I have requested 1 in the past and was only given service codes which mean nothing to me.

Children's Community Options Program (CCOP) Funding:

- Respite providers being available and the delay for CLTS to approve services at the beginning of the year. We waited the entire first quarter of the year for them to approve any services due to them stating they needed to renew provider contracts. This led to a delay in services for the child. We also did not receive any CCOP funding reimbursement until 4th quarter. This can lead to a delay in services for a child or a child not receiving the service.
- The only gap we encountered was the billing - it took a long time to get our first bill and by that time the balance had gotten rather high. It also took a long time to get the CCOPS reimbursement.