2024

Children's Long-Term Support

Annual Consumer Quality Assurance Survey Report

WAUKESHA COUNTY
HEALTH & HUMAN SERVICES

Table of Contents

Executive Summary

Waukesha County Department of Health and Human Services (HHS) completes an annual Consumer Quality Assurance Survey within the Children's Long-Term Support (CLTS) program area.

The CLTS 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:

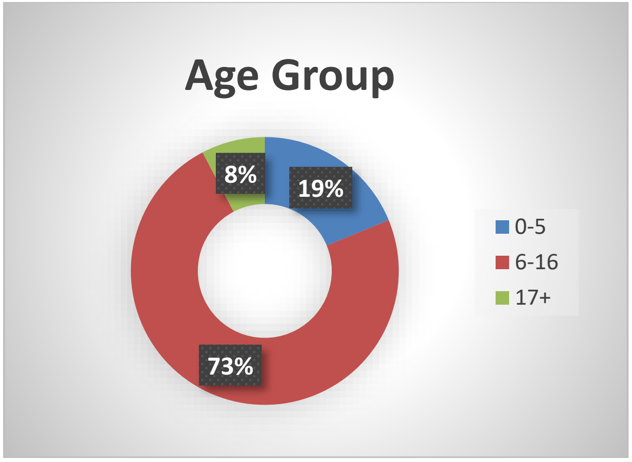
https://events.waukeshacounty.gov/Committee

Survey administration began in 2016. From 2017 to 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 CLTS program within that calendar year. If a family has more than one child involved in the CLTS 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, 2024."***

A total of 234 caregivers responded to the age group question, with the findings shown in **Figure A**. Most caregivers (172) reported their child was in the 6-16 age group, (44) indicated their child was aged 0-5, and (18) said their child was 17+.

Figure A

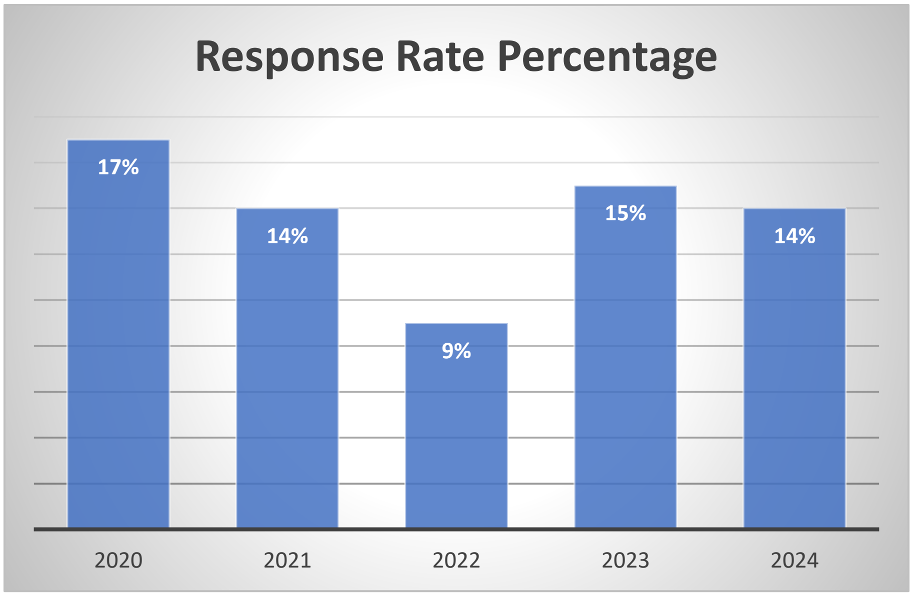


The survey consists of three sections. The Service Coordination and Program Specific sections include 13 statements which caregivers are asked to rate each statement on a 5-point scale: Strongly Disagree (1), Disagree (2), Neutral (3), Agree (4) and Strongly Agree (5). The General Comments section provides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

In January 2025, 1396 parents/guardians received an email which included a website link and a QR Code to access the annual survey electronically. In addition, we added a feature where families will get an email response upon survey completion confirming their submission. We sent 61 paper surveys by US mail to parents/guardians who did not have a valid email address. We also sent 205 letters with the survey link/QR Code by US Mail to families discharged from the CLTS program in 2024. This increased the total number of surveys sent to CLTS families by email or a letter in the US mail to 1662.

For the 2024 survey, 234 surveys were received electronically. This is an increase in the number of surveys we received in 2023 (215). **Figure B** captures the response rate from 2020-2024. This year's response rate decreased slightly from the year prior. The effort made to offer feedback opportunities to consumers in electronic format has increased the response rate from 9% in 2022, to 15% in 2023, and 14% in 2024.

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, with improvement noted in multiple areas in 2024.
- Service coordination and program outcomes are areas of strength, and the transition to adult services showed improvement again in 2024.
- Perceived self-involvement in service plan development/outcomes remains high, with 94% of caregivers endorsing "Strongly Agree" or "Agree." (Q1)
- Average levels of satisfaction with service coordination increased one to three tenths of a point in 2024:
    - (Q2) Increased by .3 in terms of providing useful feedback, information, and resources.
    - (Q3) Increased by .3 in understanding the program.
    - (Q4) Increased by .2 in timely response to requests, questions, and concerns.
    - (Q5) Increased by .2 in follow-through with requests, questions, and concerns.
    - (Q6) Increased by .2 in assisting with meeting the needs of the child and family.
    - (Q7) The amount of time available level of satisfaction increased by .1 from the previous year.
- Most caregivers (89%) 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, 2024. Survey responses (Q8) increased in 2024 indicating families felt more supported by the service coordinator with this transition. There was improvement in survey responses (Q9) in 2024 showing families felt more prepared for the transition to adult services. (Q8) and (Q9) responses were the highest in the past 5 years.
- The response to (Q10a) , "While waiting to receive services, my family was able to address the extreme health and safety concern(s)." increased from 3.8 in 2023 to 3.9 in 2024 indicating improvement in the family's ability to address any health and safety concerns while waiting to receive services from CLTS vendors.
- The proportion of caregivers indicating that the CLTS program served to improve overall day-to-day functioning (Q11) and to support goal achievement (Q12) increased in 2024. The response in the "Strongly Agree" and "Agree" categories increased (Q11) from 72% in 2023 to 76% in 2024 and (Q12) from 66% in 2023 to 72% in 2024.

2024 Program and Practice Adjustments

Data gathered through the survey process is utilized for continuous quality improvement efforts. The CLTS 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 CLTS Program continues to be proud that we at a continuous enrollment status having not have a waitlist for program enrollment since March of 2023. In order to remain serving youth at this rate our team of leadership and service coordinators work incredibly hard to train and support a team of 54 service coordinators to serve the 1644 children enrolled on the last day of the calendar year 2024. Our projection for enrollment in 2024 fell short as we had an unexpected disenrollment rate which went up from 87 youth in 2023 to 191 in 2024. This is an increase of 120% from last year. In reviewing the disenrollment reasons, it is inconclusive that there is a programmatic theme as to the specific reason for the increased disenrollment as reasoning is spreads across a wide variety of categories. In order to address feedback provided in the 2023 survey and wanting to reduce the staff turnover rate, the decision was made in 2024, that we would add additional service coordinators to support reducing caseloads sizes for enhanced service delivery for CLTS families by adding an additional 2 Supervisors to help onboard and train newly hired staff and 8 additional Service Coordinators to work directly with youth and families.

This picture represents about half of our CLTS team dedicated to supporting youth and families in Waukesha County.

Question 9 on Page 15, states, “My child was 17 years old as of July 1st, 2024; I feel that as a family we are prepared for the transition to adult services”. The average response in 2023 improved to 3.8 – closest to Agree. The average response in 2024 improved to 4.0 – Agree. This response in 2024 has been the highest in the past 5 years. Over the past several years, CLTS partnered with the Aging and Disability Resource Center (ADRC) to provide a teamed approach to helping supporting families during this time of transition. These efforts have yield positive results. The ADRC also has a Transition Guide to assist families. Transition resources can be found at: https://www.waukeshacounty.gov/health-and-human-services/aging-and-disability-resource-center-adrc-of-waukesha-county/youth-in-transition/#faq.

The Children’s Long Term Support 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, decision were made to abolish the two existing Divisions within Health and Human Services. The decision was made to realign programmatic areas together so programs which provide case management, referral services, are funding by primarily by Medicaid are in one division called Child and Youth – Coordinated Services. These program areas are the Children’s Long Term Support Waiver Program, Children’s Community Options Program, Youth Comprehensive Community Services, and Birth to Three. The other division named Child and Youth – Family Services has all programmatic services which are typically non-voluntary in nature and court ordered such as Child Protective Services/Foster Care, and Youth Justice. This transition in 2024 was successful and has already resulted in better collaboration for those youth who are dually enrolled in Comprehensive Community Services and the Children’s Long Term Support Waiver Program. In 2025, we will look ahead towards ways that can also enhance the service delivery for those youth who are dually enrolled in Birth to Three and CLTS. Along with this realign, it was determined that we would drop the program name of Children with Special Needs, also known as CSN and refer to ourselves solely as the Children’s Long Term Support Waiver Program. Therefore, you will see this document is no longer called the Children with Special Needs Annual Survey but rather the Children’s Long Term Support Program Annual Survey.

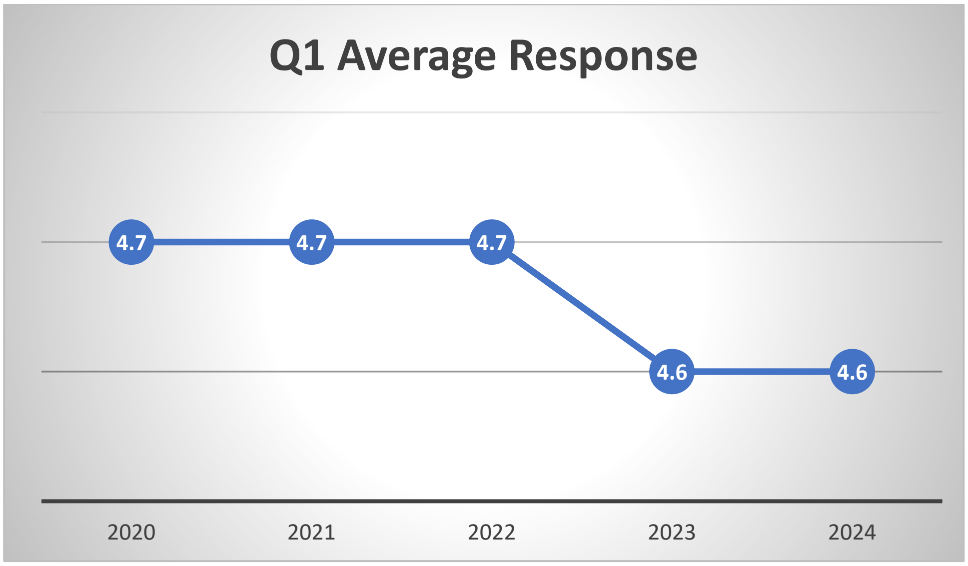
Two of our primary goals in 2024 as result of survey feedback was to add additional service coordinators which in turn would reduce caseload size to stabilize the response and reimbursement timeframes for CCOP requests. Our program also made the determination to convert all program operations to all electronic processes to eliminate paper records. This also included an updated to our release of information process for families, from families signing one release for each provider listed on the Individual Service Plan to a single document which allows us to communicate as needed with providers to facilitate case management duties. This update has led to a time and efficiency savings for both families and staff. 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 remained the same from the previous year. A total of 220 caregivers (94%) selected "Agree" or "Strongly Agree" in 2024.

Figure 1

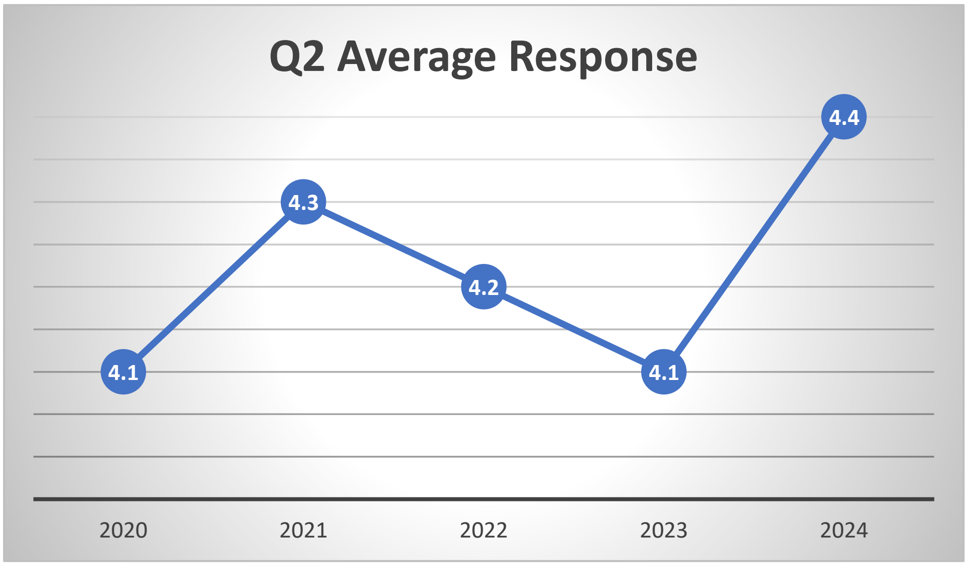


Q1	2020	2021	2022	2023	2024
Strongly Agree	86	85	72	137	175
Agree	23	24	25	69	45
Neutral	3	1	2	4	5
Disagree	0	1	1	1	6
Strongly Disagree	1	0	0	3	3
n=	113	111	100	214	234

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 (4.4) is closest to "Agree", and this response rate has increased significantly from the previous year. The response in 2024 has been the highest in the past 5 years. A total of 208 caregivers (89%) selected "Agree" or "Strongly Agree" in 2024.

Figure 2

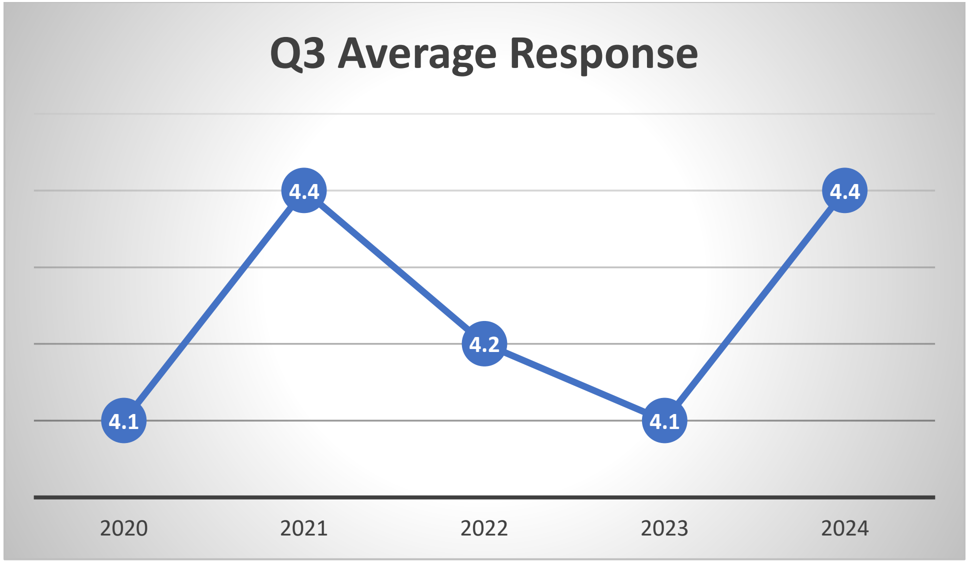


Q2	2020	2021	2022	2023	2024
Strongly Agree	50	60	48	93	143
Agree	39	34	34	81	65
Neutral	18	9	12	21	9
Disagree	4	7	2	9	8
Strongly Disagree	3	2	3	10	9
n=	114	112	99	214	234

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 (4.4) is closest to "Agree", and the average level of agreement has increased significantly from the previous year. A total of 202 caregivers (86%) selected "Agree" or "Strongly Agree" in 2024.

Figure 3

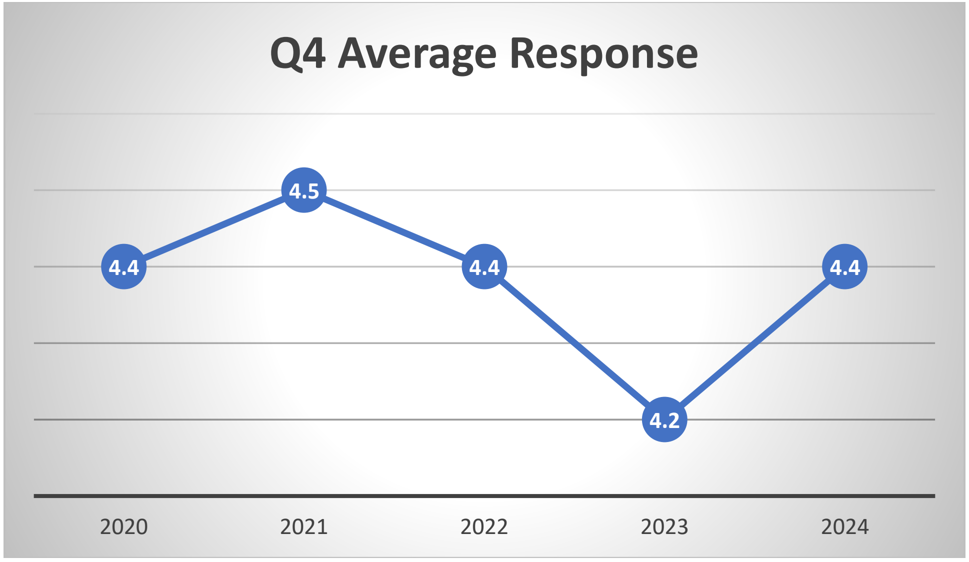


Q3	2020	2021	2022	2023	2024
Strongly Agree	48	68	49	98	143
Agree	47	29	34	72	59
Neutral	7	10	10	22	16
Disagree	7	4	1	10	7
Strongly Disagree	4	1	6	12	9
n=	113	112	100	214	234

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

Figure 4 shows that the average response (4.4) is closest to “Agree”, and the average level of agreement has increased from the previous year.   A total of 198 caregivers (85%) selected “Agree” or “Strongly Agree” in 2024.

Figure 4

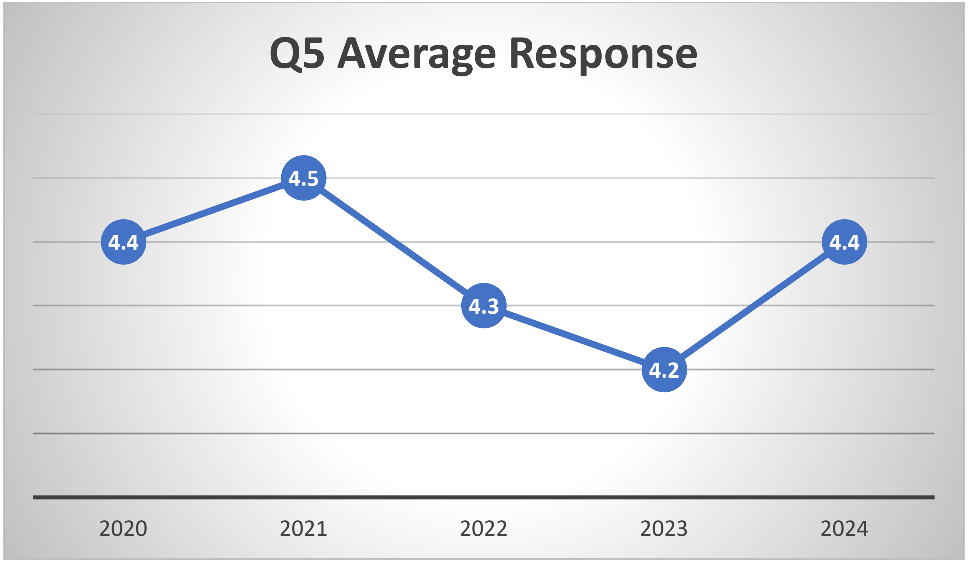


Q4	2020	2021	2022	2023	2024
Strongly Agree	65	71	59	111	152
Agree	35	30	28	70	46
Neutral	5	5	6	14	18
Disagree	5	2	4	12	10
Strongly Disagree	3	3	3	8	7
n=	113	111	100	215	233

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

Figure 5 shows that the average response (4.4) is closest to “Agree”, and the average level of agreement has increased from the previous year. A total of 202 caregivers (86%) selected “Agree” or “Strongly Agree” in 2024.

Figure 5

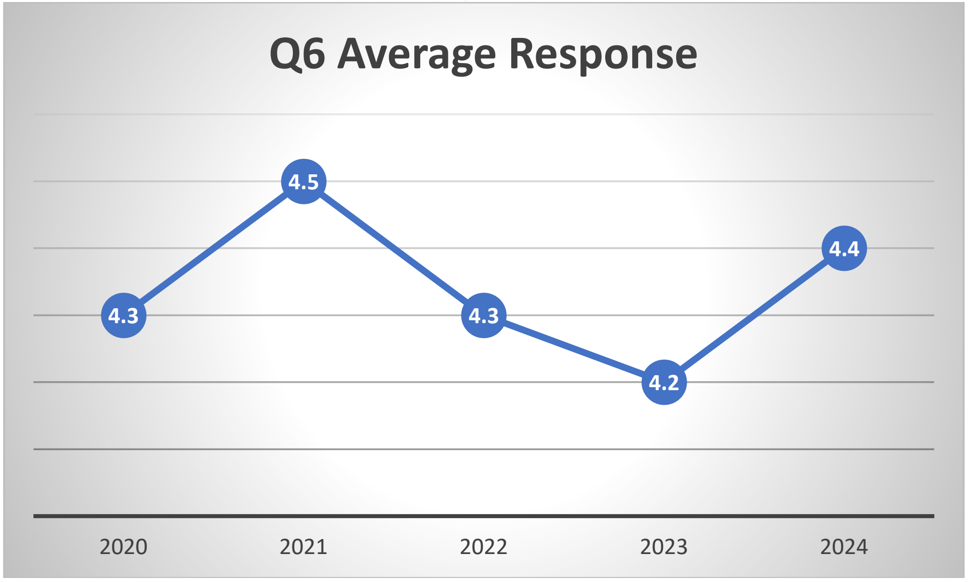


Q5	2020	2021	2022	2023	2024
Strongly Agree	67	68	56	104	146
Agree	30	36	28	78	56
Neutral	11	5	8	14	17
Disagree	3	0	5	10	4
Strongly Disagree	3	2	2	9	11
n=	114	111	99	215	234

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

Figure 6 shows the average response (4.4) is closest to "Agree", and the average level of agreement has increased from the previous year. A total of 203 caregivers (87%) selected "Agree" or "Strongly Agree" in 2024.

Figure 6

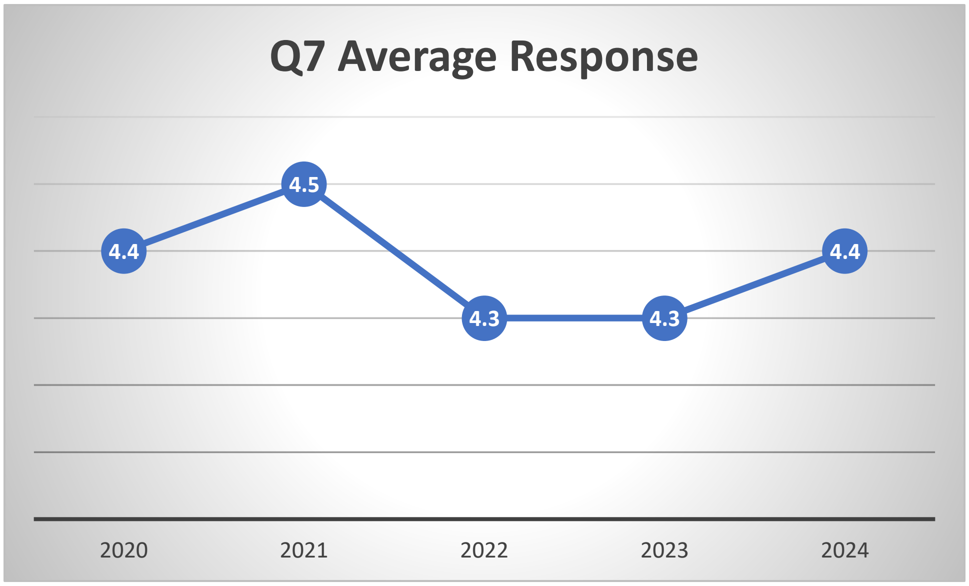


Q6	2020	2021	2022	2023	2024
Strongly Agree	63	68	48	107	152
Agree	36	36	40	74	51
Neutral	7	5	6	16	15
Disagree	1	0	1	6	5
Strongly Disagree	5	2	4	12	10
n=	112	111	99	215	233

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 (4.4) is closest to "Agree", and the average level of agreement has increased from the previous year. A total of 204 caregivers (87%) selected "Agree" or "Strongly Agree" in 2024.

Figure 7

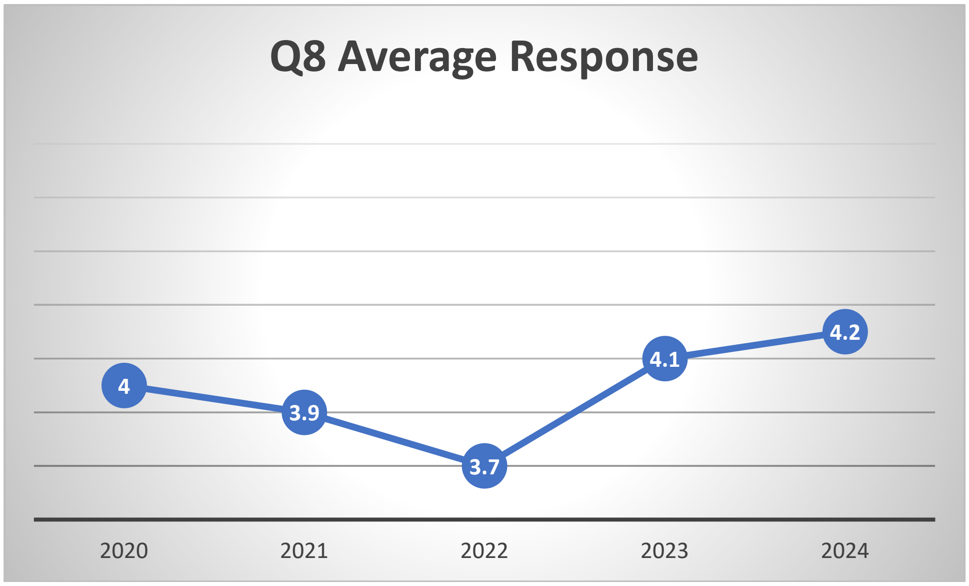


Q7	2020	2021	2022	2023	2024
Strongly Agree	67	71	50	111	151
Agree	37	30	35	73	53
Neutral	6	7	8	15	17
Disagree	1	2	5	6	5
Strongly Disagree	3	2	1	10	8
n=	114	112	99	215	234

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 (4.2) is closest to "Agree", and this represents an increase in response from the previous year. The response in 2024 has been the highest in the past 5 years. Note the total number of caregiver responses to this question was 18 in 2024.

Figure 8

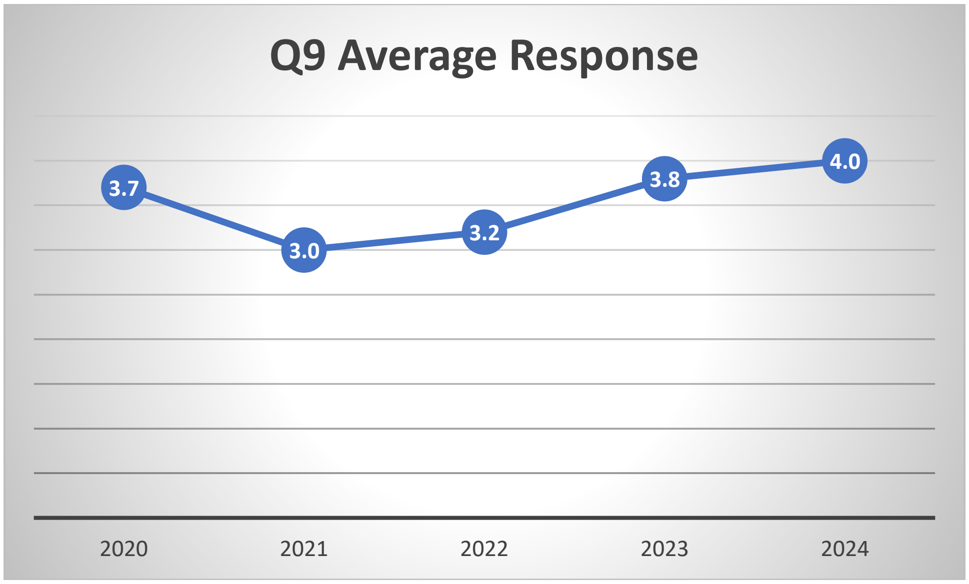


Q8	2020	2021	2022	2023	2024
Strongly Agree	2	6	7	6	8
Agree	1	3	4	0	8
Neutral	0	1	3	2	0
Disagree	1	0	0	0	2
Strongly Disagree	0	2	3	1	0
n=	4	12	17	9	18

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 (4.0) is "Agree", and the average response has increased since the previous year. The response in 2024 has been the highest in the past 5 years. Note the total number of caregiver responses to this question was 18 in 2024.

Figure 9

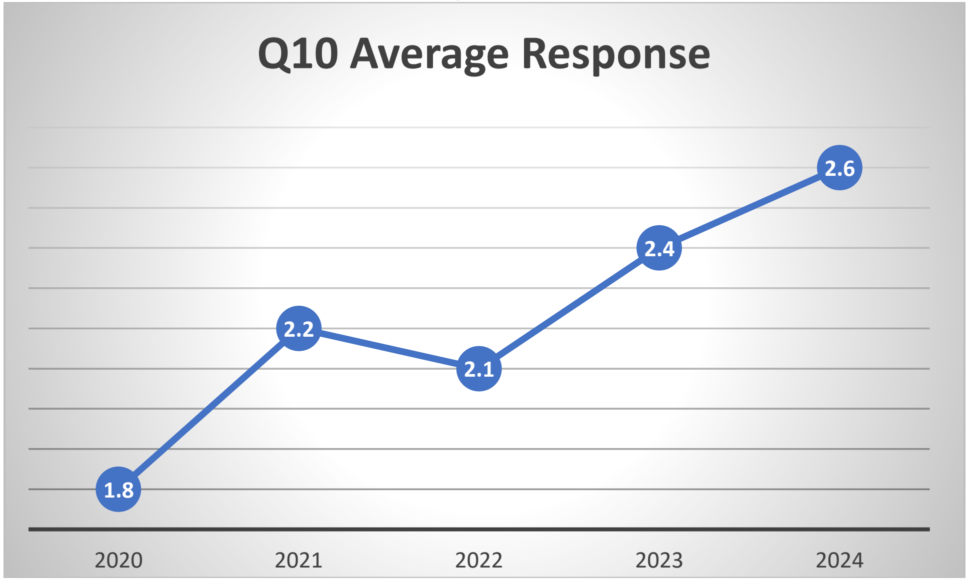


Q9	2020	2021	2022	2023	2024
Strongly Agree	3	1	3	2	4
Agree	2	3	2	5	11
Neutral	2	0	5	1	2
Disagree	2	1	1	0	1
Strongly Disagree	0	2	2	1	0
n=	9	7	13	9	18

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 (2.6) 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 233 responses, 170 (73%) 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 2023, 75% 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

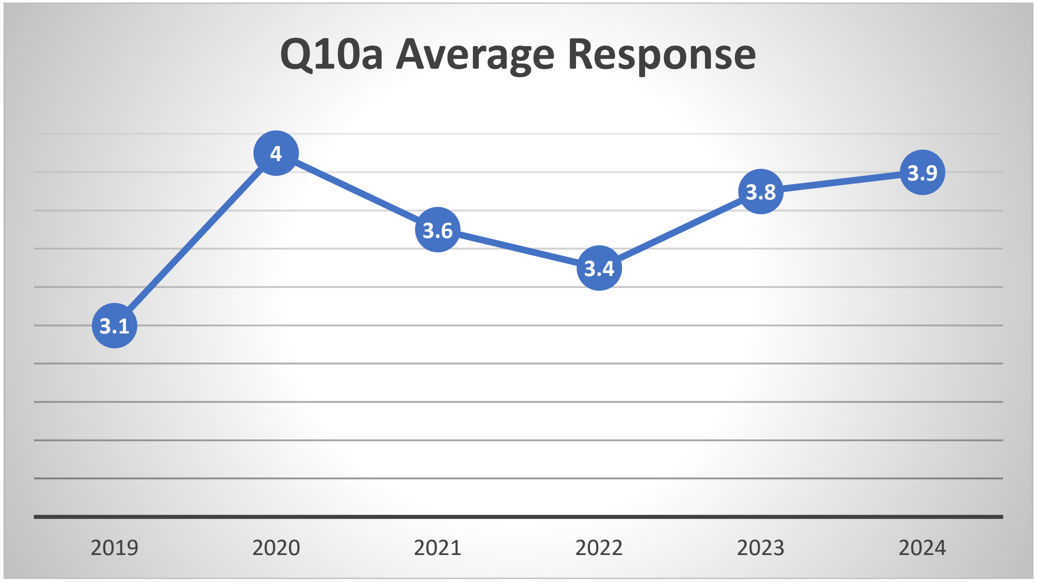


Q10	2020	2021	2022	2023	2024
Strongly Agree	10	10	7	18	32
Agree	2	12	10	34	31
Neutral	12	12	14	36	42
Disagree	22	19	16	57	62
Strongly Disagree	64	46	44	67	66
n=	110	99	91	212	233

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 (3.9) is closest to "Agree." The average level of agreement has increased from the previous year (3.8) 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 63 in 2024.

Figure 10a

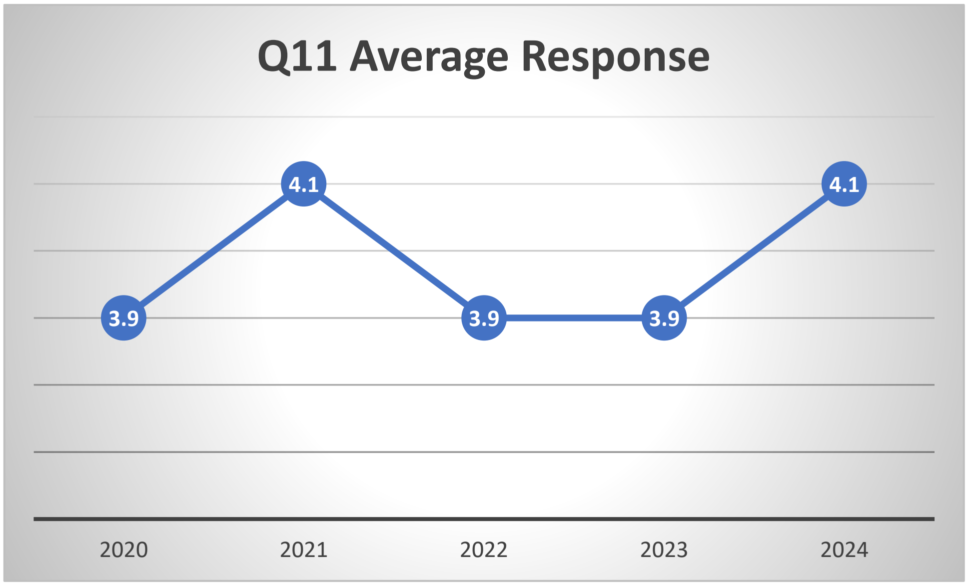


Q10a	2020	2021	2022	2023	2024
Strongly Agree	6	5	6	14	24
Agree	2	6	6	24	19
Neutral	2	4	5	7	12
Disagree	2	1	4	5	6
Strongly Disagree	0	2	2	2	2
n=	12	18	23	52	63

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 (4.1) is closest to "Agree", and that the level of agreement with this statement increased since the previous year. A total of 177 of the caregivers (76%) endorsed "Agree" or "Strongly Agree."

Figure 11

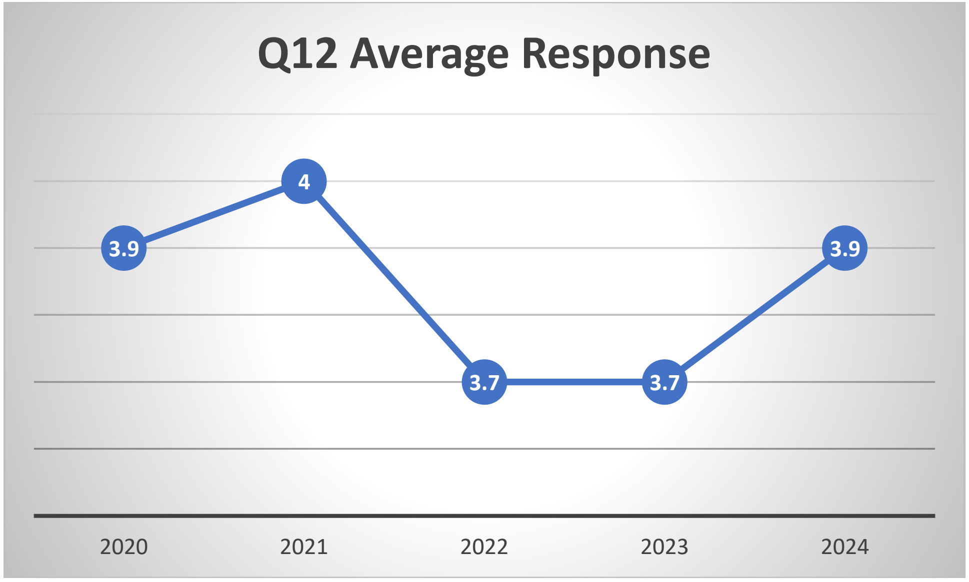


Q11	2020	2021	2022	2023	2024
Strongly Agree	39	42	29	69	99
Agree	42	48	37	85	78
Neutral	25	17	23	45	40
Disagree	3	2	5	7	13
Strongly Disagree	4	2	2	9	4
n=	113	111	96	215	234

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 (3.9) is closest to "Agree," and responses to this item have increased since the previous year. A total of 169 of the caregivers (72%) endorsed "Agree" or "Strongly Agree."

Figure 12



Q12	2020	2021	2022	2023	2024
Strongly Agree	30	32	25	48	69
Agree	50	53	33	93	100
Neutral	24	21	28	50	45
Disagree	5	2	6	13	13
Strongly Disagree	4	1	4	11	7
n=	113	109	96	215	234

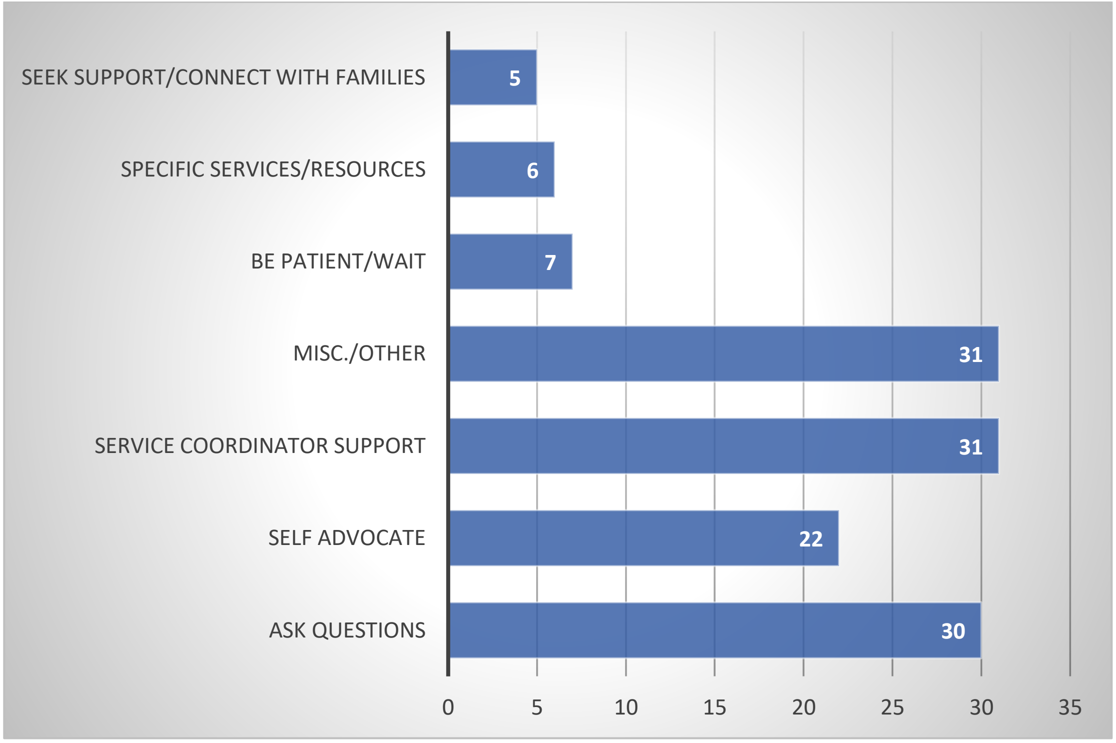
General Comment Results

In addition to rating Service Coordination statements, caregivers were also asked three open-ended questions to garner their thoughts and opinions in narrative form. Responses are shown verbatim except when identifying information was given for the names of clients, providers, and staff, or information that would disclose HIPAA information. Those statements have been redacted by a solid black square. Due to the nature of concept of verbatim, grammar and spelling errors could be present. 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 234 completed surveys, 132 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 recognize Service Coordinator Support (31), Ask Questions (30), and Self-Advocate (22). The Misc./Other (31) category offered more personal advice and feedback to families new to the program. These four themes (114) accounted for 86% of the 132 responses to this open-ended question.

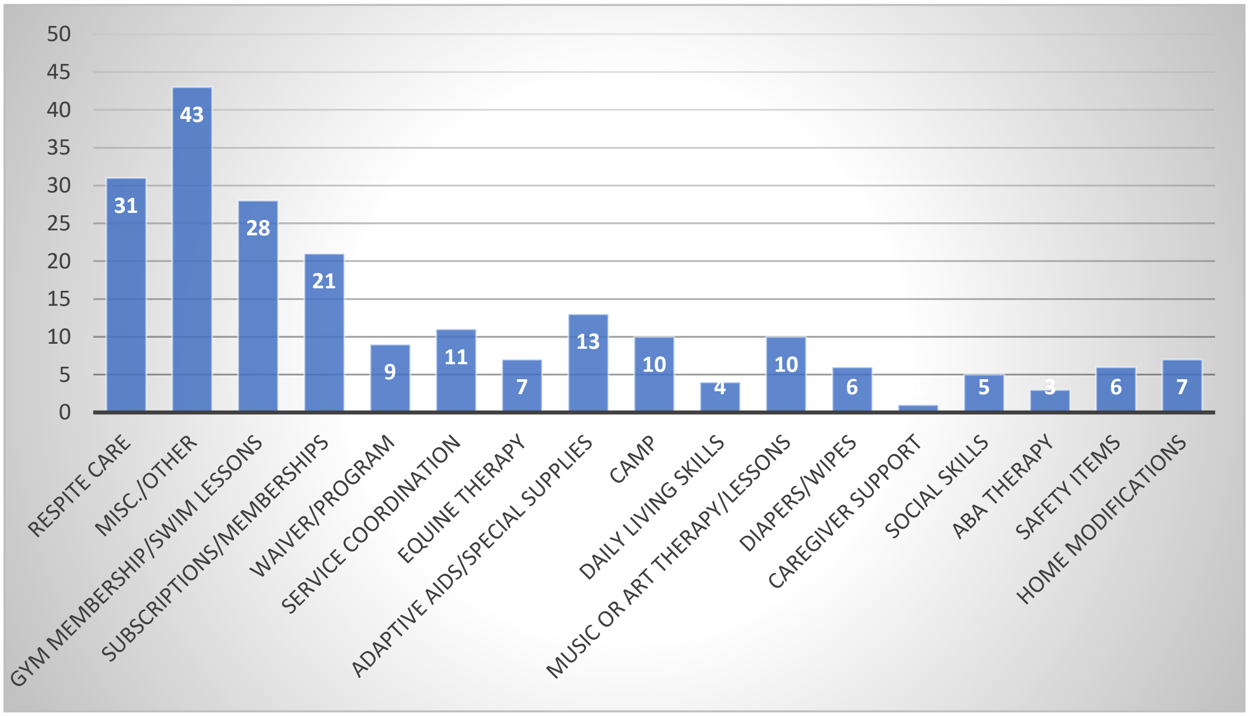
Figure 14



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

Out of 234 completed surveys, 215 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 (31) which accounted for 14% of the total responses. Positive comments were also received regarding Gym Membership/Swim Lessons (28) which accounted for 13% of the total responses. The Misc./Other (43) category offered more personal advice and feedback regarding services or supports most helpful to families.

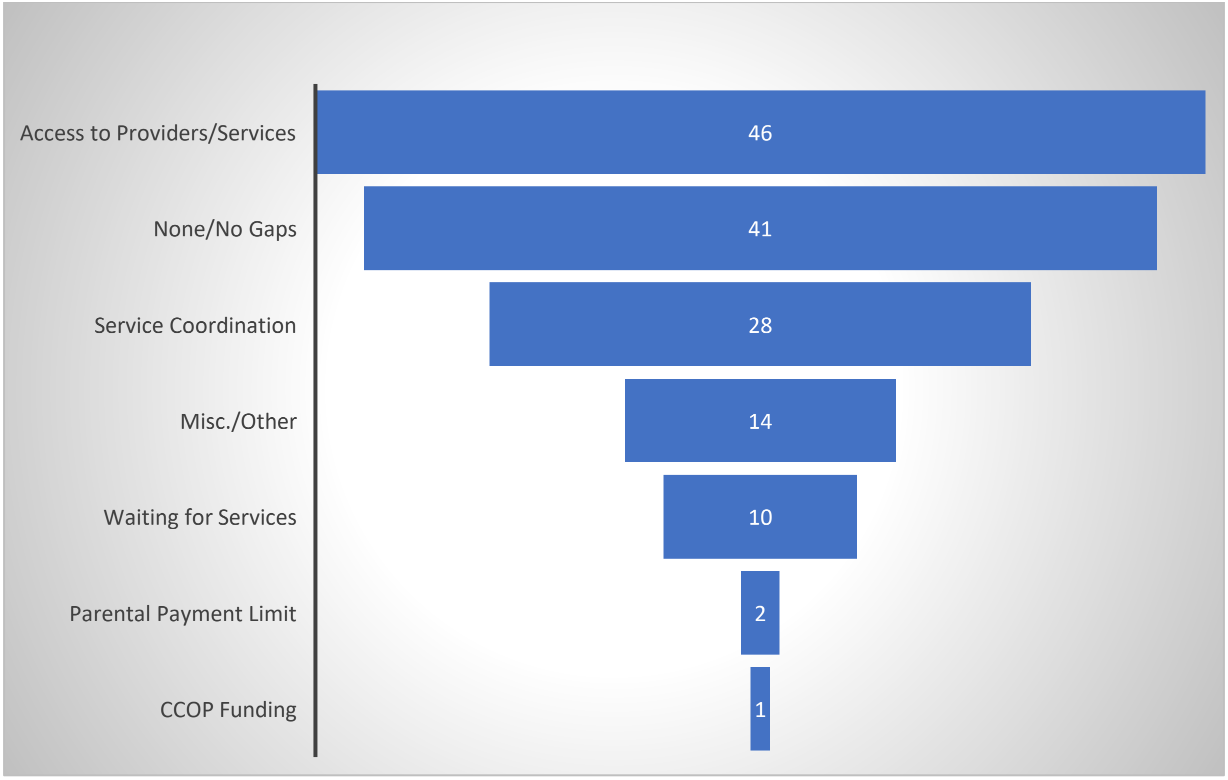
Figure 15



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

Out of 234 completed surveys, 142 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 (46) which accounted for 32% of the total responses. An area of strength was noted with 41 of the responses (29%) indicated there are no gaps in services/support.

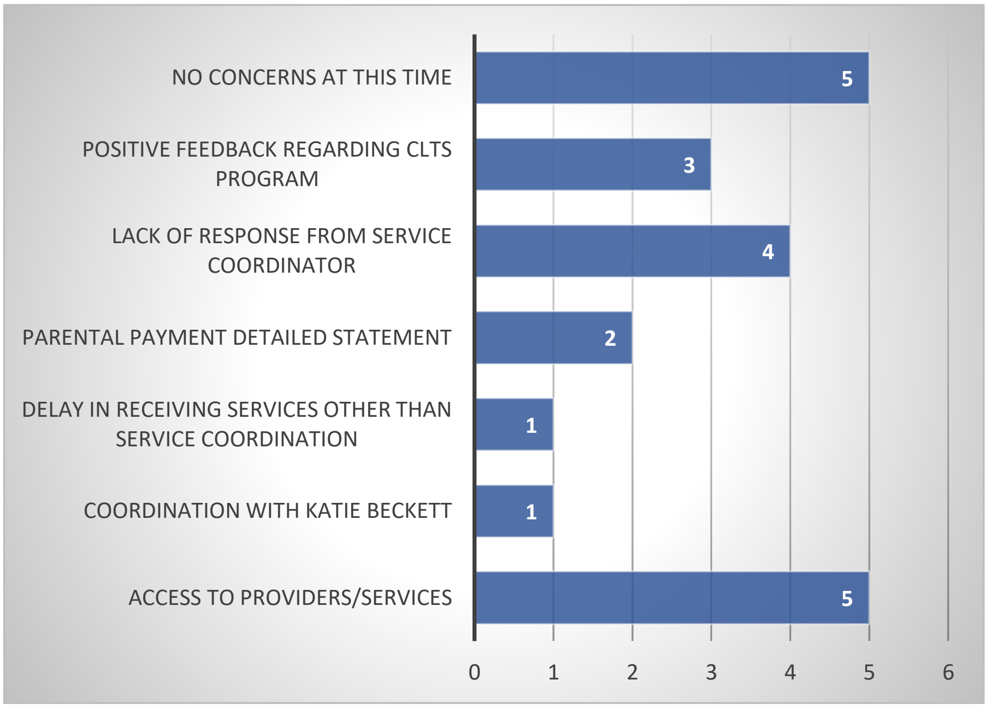
Figure 16



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 234 completed surveys, 19 caregivers replied to this question, requesting contact from a member of the CLTS leadership team. One caregiver did not respond to attempts to make contact. Note that total number of responses to this question was 18 in 2024. **Figure 17** captures frequency of responses based on seven theme categories with some caregivers providing multiple responses. The most prevalent concern identified by caregivers, was Access to Providers/Services (5) which accounted for 24% of the total responses. Another area of concern was the lack of response from the Service Coordinator (4) which accounted for 19% of the total responses. Two other response areas- Positive feedback regarding the CLTS Program (3) and No concerns at this Time (5) accounted for 38% of the total responses.

Figure 17



Appendix A

Responses are shown verbatim except when identifying information was given for the names of clients, providers, and staff, or information that would disclose HIPAA information. Those statements have been redacted by a solid black square. Due to the nature of concept of verbatim, grammar and spelling errors could be present. For purposes of this report, responses were grouped based on common themes.

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?"***

Service Coordinator Support: (31)

- Reach out your service coordinator with questions. They are so willing to help!
- If you want the best for your child, reach out and they will work with you and you will notice a difference in your child after a few visits. Just make sure if you do birth to 3 make sure it doesn't stop after their 3rd birthday. Make sure it goes through that whole year.
- It is important to ask a lot of questions and be open to suggestions of the coordinators. We are grateful to have a very responsive and supportive coordinator.
- Make sure to contact your case worker every month with updates and give them plenty of time to get back to you. Email tends to be faster.
- Be cautious in comparing benefits with residents of other counties. Waukesha provides less support than [redacted] or [redacted] counties. Your service coordinator makes all the difference. Our first coordinator was terrible but since we have started working with [redacted] we feel like we have an advocate.
- I would recommend that they reach out to their service coordinator with any questions or concerns they have. It's a lot to take in, and it's hard to understand all of the different programs there are and the regulations that apply to them.
- Be prepared to have your coordinator constantly changed.
- The coordinators do offer a lot of information and services available for your child, take on one thing at a time. It can be time consuming. Especially if you're a single parent. They offer great ideas and programs for your child BUT not every program will be the best fit for your child, you know them best. Overall, we're very fortunate to have the waiver program and appreciate what they have to offer.
- We just started with a brand-new case manager and coordinator. I have not had the pleasure of meeting our new case manager yet, the answers are based on [redacted] whom we had for several years. She would not approve adapted swim lessons for my son until I created a measurable goal for my son, it took 6 months, I called her and wore her down for about an hour before I finally got her to admit that we could add [redacted] goal. Also appeal appeal appeal, [redacted] takes pleasure in refusing supports and services to families to stay under budget.
- Always communicate with your service provider even for and about the smallest things.
- Frequent communication with your coordinator.
- Work closely with your Service Coordinator asking for very specific needs to be met: everyone's needs are different. If you aren't sure, ASK. There is usually a way for CLTS to help. We have received all sorts of resources we never knew were available since simply developing an excellent working relationship with our Coordinator, [redacted]. [redacted] is an excellent addition to our family's team, helping with my two young disabled children. When I have a need, I simply reach out to [redacted] and she is there for me and my children: it is challenging raising multiple disabled children alone, but with [redacted] on our side, the weight of it is lighter! ASK! You never know how you can be helped by your Service Coordinator unless you ask.
- Lean heavily on your coordinator. Our Coodinator, [redacted], is the most knowledgeable, capable and caring resource on [redacted] entire team of providers.
- Work closely with your service coordinator.
- Maintain a good relationship with your service coordinator!
- To lean on the Coordinator and their understanding of what offerings exist based on the child's needs. Always ask about if something would be covered, you never know.

- Hang in there, and stay on your service coordinator to ensure your requests are met.
- The service coordinator changes in 2024. [redacted] the service coordinator who began the year was terrible and an ineffective communicator and assistant; in the contrary, since [redacted] began, support and communication has improved tremendously in just the few short months she has been on the job.
- Be sure to tell your service provider what you need and the challenges you are having. You never know what resources they can provide.
- Work closely with your service coordinator. They are here to help.
- Follow the process. Work with the social worker. My child has mental health needs vs other medical issues. With mental health issues it it's important to remember that these issues won't resolve over night. It's a marathon, not a sprint. The small steps in the right direction will add up over time creating larger overall improvements.
- Request [redacted] she is AMAZING. Her immediate connection to our family and daughter was wonderful. She is so genuine and really knows what she is doing. We are so thankful she is our worker !!
- communicate withbyour coordibator for the servuces youbthing will suit your child
- Reject [redacted] as service coordinators from the "wrap-around" program -- they are being used to extend response times and increase denial of services/requests. Staff with minimal experience are required to secure approval from several steps above and are being given directives in full contrast to direct [redacted] service coordinators.
- Talk to your Coordinator there is a ton to offer! Include conversations with your physician and school support and the coordinator. Mine has been exceptional!
- Be open and honest with your case manager. If you let them know what's going on they will offer suggestions to help your immediate needs.
- [redacted] is great and wish everyone could have her
- Run all supports and services past your coordinator. Don't initiate anything without their approval.
- Ask your coordinator about resources that your child can take advantage.
- That there are so many resources I didn't even know about until my service coordinator showed me and that there is different services and programs for all kids. Our service coordinator is just wonderful and is so fast to reply back answering my questions and providing resources. My service coordinator helped me identify services for my son that would be helpful and they were !
- Have patience and compassion for your case manager. Our family was bounced around to several different case managers who knew we were a temporary responsibility and it showed through their efforts and time and attention given to my concerns. Now that we have our permanent case worker (until she quits) things are moving in the right direction. More case managers are needed to handle the extensive work load per family so that families can be better served and attended too. Keep all of this in mind when you become part of CTLS. It's a wonderful program but it has limitations.

Misc./Other: (31)

- You need to be involved and the whole family needs to be involved not just the child.
- I am still new and trying to figure this out.
- Don't rely on this as a way to help. Maybe after a year you might get a referral or follow through with a purchase but don't count on it.
- Try everything offered!!!
- Focus on making sure your child receives the support they need to succeed in life. They're still the same child they were before their diagnosis, the diagnosis will help with getting your child the support they need.
- Trust the process. It takes time to establish services appropriate to your child. One everything is in place, services begin and you can relax knowing you are doing the best thing for yourself and your child. Set reminders for renewal ahead of time.
- It's been very confusing trying to navigate Katie Beckett and renew.
- We are new to the program so I cannot gauge the goals piece yet
- Great program. Just takes a bit to navigate through.
- This program has been very helpful to us. We have been able to provide things for our daughter that we would be very challenged to provide without the program.

- Do not waive CLTS coverage when your child is a newborn. Even if you are not using it immediately, it is a hassle to re-enroll if you qualified right away.
- Be honest with struggle you have.
- To stay and achieve the goals of your children's and to work along with the program.
- Definitely use their services! There are so many benefits for our son that I didn't even know existed because of this program!
- This is an amazing program, and I wish we had heard about it in elementary school and started our daughter much earlier.
- Investigate all areas of services offered.
- Open communication is very important for success. But aside from that it's a great program- goal setting for the child
- Use the resources available to you. We are lucky to live in a state that provides these types of support.
- I am so thankful and forever grateful for this program.
- The goals set forth are long term and as I see are not measured annually because the programs our nephew attends are designed for long term improvement. Granted, we do short gains that have evolved from the programs he is in so that is a win as well!
- Once you start getting the help is a good feeling knowing that someone else is there to help and support you and the family.
- None at this time.
- I am too new to the program and can't really offer any advice.
- There are more opportunities for assistance out there than you are aware of.
- Honestly, the program hasn't been really helpful. It's not clear what's covered and what's not. What's even more frustrating is that depending on the county you live in different things are covered - which makes no sense.
- I don't know. I am new to the program.
- When we enrolled, it took months to get things set up. We called in July and didn't have an intake until September. In October we got a call saying that we had qualified for services and would be assigned a service coordinator soon. That didn't happen until mid-December, at which point the service coordinator said she couldn't meet with us until after the holidays. We met in January and didn't receive any information about services that we could use until February 7. We haven't received any sort of plan relative to his goals or what we're able to use. This process has taken over 6 months and we still don't have a lot of clarity or understanding of it.
- None
- To keep in mind what changes you have made to protect your child because they can help improve upon that!
- this program intends to help families and I am grateful for this program. is a big hope for my son.
- Not sure

Ask Questions: (30)

- Ask for help, its okay.
- It is important to ask a lot of questions and be open to suggestions of the coordinators. We are grateful to have a very responsive and supportive coordinator.
- Ask lots of questions. Don't be shy about asking for help - that is why they are here!
- Ask questions. Make sure you understand and feel comfortable with your child's plan and if there is a benefit you are looking for ask. I have learned so much through our service coordinator.
- Ask a lot of questions.
- Ask questions.
- You need to ask very detailed questions and keep pushing for information. We were told of all these opportunities that are available but when we ask for them they were not available or there was no flow-up
- ask a lot of questions and ask for what services are available
- Ask lots of questions because the process can be very confusing.
- Communication is key. If you have questions or concerns then ask. You will always get an answer.

- Ask questions! Your caseworker will work diligently to answer any questions you may have.
- Communication with your coordinator is key. Always ask questions.
- Make sure to ask questions.
- To reach out and find out what help is available. At the beginning of the journey you don't even know what questions to ask or what resources would help your family.
- Don't be afraid to ask questions.
- Look into every program and don't be afraid to reach out for any questions. Someone is always so helpful and willing to help.
- Don't be afraid to ask for help. Nothing is too big or small. Even if it is something they can't do, they look for alternative options.
- don’t be afraid to ask for help. Nothing is too big or small. Even a tiny little thinglike chewlry can help with these littlest things and be a big impact.
- Ask if things are covered that you wouldn't think would be before purchasing. Ask about lifestyle/wellness activities like swim lessons. I was surprised to find out they offer that.
- Research all that’s available and ask questions.
- Ask lots of questions. There's a plethora of information out there but it's difficult to wade through a lot of it to get to what's really important for your child.
- Ask questions, recognize you are the expert in your child's needs, collaborate with the Service Coordinator and learn all of the available supports through the program.
- Always ask for anything, the worst they could say is no.
- When navigating the program, asking questions and practicing patience are essential components of the journey. While the process may seem daunting at times, asking questions and exercising patience empower us to make the most out of the program. We are advocating for our child’s future, and that persistence will pay off.
- Ask questions. There are a lot of services offered that you may not be aware of.
- Ask alot of Questions and become as educated yourself as you can because even the coordinators aren't always educated about all the options. That is not necessarily bad. I just believe the resources and opportunities are ever changing.
- Ask questions and speak up when you are confused on something.
- It never hurts to ask, no matter how big or small!
- Don’t be afraid to ask anything.
- Don’t be afraid to ask questions.

Self-Advocate: (22)

- Educate yourself on what is available, ask questions, speak up and advocate for your child.
- Be clear about what your child or family to be able to do - not just products or services you think they need.
- Spend time familiarizing yourself with what the program can help with.
- Think outside of the box and ask for anything you need.
- Explore all options and don't be afraid to ask for different equipment that works for your child.
- Do your own research about what can and can not be covered to know what to ask for and how CLTS should code things to get coverage.
- Get educated on your rights and advocate for your child.
- Take every advocacy education class offered through [redacted] because you will need it in order to battle your CLTS Service Coordinator's [redacted] as they are the only person to make decisions for the ISP and all requests. The Service Coordinator is simply your Admin Asst performing data entry without any autonomy for decision-making on any of your questions or concerns. The parent is the sole expert of the child with disabilities and needs to understand all legal jargon and strategy in how to make requests that align with the CLTS Handbook and be prepared to report to a judge & state authorities for all of the denials Waukesha County CLTS [redacted] will provide to you every single year.
- Do your research and look up everything before you decide.

- If you want to do everything to help your child(ren) enroll in this program! They give you information and can help you get anything you may need.
- Be versed in all the services. Use all the services.
- They have a lot to offer. You have to listen to what they are offering your family. Then you talk to you child, what they are offering to see what they really would to do. Sometime what is offered is something you think your child would like.
- To parents: don't wait for your school's guidance counselor's or special ed department or teachers to identify the need to obtain transitional services after high school. Go to disability and transition services fairs that are offered in the community, and go to social services directly to obtain information. Do this earlier than the last year of high school.
- You are the only advocate for your child.
- Be sure to understand all the different things that are available to you.
- Be sure to ask lots of questions and get everything in writing in case you end up overwhelmed during meetings.
- Being your own advocate and educating yourself is really the only way to get anywhere.
- Make notes of your concerns and needs. It’s hard to remember with all of the information you’re given.
- Learn what programs are available- you may not know a program could be helpful if you don’t know about it.
- Do your research.
- Be sure to direct them to the online explanations of the many services available to them which also describes what each program can do for them and who to contact.
- Stay on top of things.

Be patient/Wait: (7)

- Be patient it’s confusing. I feel like it’s a ton of work so we don’t do much with it because of how hard everything is in life already.
- Be patient. Requests, services and programs can take time to receive.
- Keep at it! It takes a very long time to get started and get going. Be the squeaky wheel.
- Be patient, things will fall into place once all the paperwork and formalities are done.
- Be patient.
- When navigating the program, asking questions and practicing patience are essential components of the journey. While the process may seem daunting at times, asking questions and exercising patience empower us to make the most out of the program. We are advocating for our child’s future, and that persistence will pay off.
- Don’t get to excited, you’re not going to get anything!! If you need it, there will always be a reason they can’t do it for you.

Specific Services/Resources: (6)

- Utilize respite care if your child qualifies because it is so important to take a break, reconnect with spouse or other children. You cannot pour from an empty cup.
- Ask about the programs that are offered to your child through the waiver. It can help fund clubs and programs like swimming for your child to learn vital experiences.
- Out of school programs for our kids closer to the subberbs in Waukesha County.
- If you asked for monetary assistance for a museum membership but feel you barely used it, then don't ask for it following year.
- I would love to recommend the Music therapy since I saw a great improvement of my son since he started the Music Therapy.
- Social programs.

Seek Support/Connect w/Other Families: (5)

- Get involved with other experienced parents whom have been in the program and use their knowledge.

- /talk to other parents with similar experiences
  /discuss with the coordinator all needs
  /write down all the activities of the special needs person
- Keep good records of all medical paperwork! Network with other parents as sometimes there are services out there your caseworker might not have heard of yet and be sure to share of programs you hear about to your caseworker so they can share with other families! It takes a community to make the program successful!!
- Speak to other families with children of special needs that is how I found out about most of the benefits available to our child we didn’t know about.
- Try to find support groups or other families that are or have gone through similar experiences.

Appendix B

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

Misc./Other: (43)

- Haven't used any of the services yet but planning to.
- Birth-3. We have seen such an improvement in our son since we started the birth to 3 program.
- Have not received too much the past year. We had another coordinator quit and a new coordinator start in December. [redacted] is great.
- Our old coordinator provided great information however follow up was lacking... I have reached out to the new social worker with questions and follow up and have not heard back... they also never reached out and introduced themselves. very disappointing.
- None
- Identifying local programs.
- I've had to do most everything on my own - so none yet
- We're still waiting for services so we can't say.
- Tools for home, activities through autism society. We have asked for other passes to join in public social spaces and classes to further support our child. We're told that neither are supported in the program.
- [redacted] access and support as well as Amazon purchases.
- Therapy
- A goal was to get my daughter physically active and we are incredibly happy with the program with [redacted]! We are also so grateful for the new [redacted] for my daughter as her old one was so old we couldn't get her any new learning games and she had outgrown what was on her old iPad.
- Those that involve social interactions for our daughter. Those that keep her safe.
- Financial
- Na
- N/a
- Therapeutic and social supports
- So far everything
- Birth to 3
  Future swim classes
- In home therapy
- Utilizing mentor for child to support US as parents with necessary free time away from the stress of parenting
- Having my child go somewhere on off days
- all
- The extra curricular activities have been able to give my children an Outlet.
- Theraputic support for parents.
  Respite care for parents
  Financial support to offset costs
- [redacted], helping to obtain an [redacted]. Supporting different ADHD support items so far.
- Therapy's
- Our son suffers from depression, anger, things from the past. He needed someone to talk to about, his father the school bulling what was happing to him. He has a hard time trusting people. With the mentors he was able to listen to the good things in our family. When he plays with cousin [redacted] he dose not fight with him anymore. It is nice to see it.
- Medication insurance was very helpful. Specialized [redacted] helped our son tremendously.
- The ones that give my child the ability to engage in the community and help academically.
- I like that services/meetings can happen in the home.
- Repite and connections to the community with what options may be available.
- Still waiting.
- CCOP

- Mentor
- We have not received any services or support yet.
- Their commitment
- The recourses that are availy
- I don't know, we are always denied.
- Mentor and Therapist
- Having swimming lessons and yoga.
- [redacted] membership
  Mental Health counselor
- Getting Medicaid insurance

Respite Care: (31)

- Respite this year has been awesome. Our whole family loves our respite girl, and she has created amazing bonds with the kids.
- Respite, sensory gym, and a safety fence that will be installed this spring.
- Respite and child care and home modifications.
- Respite care
- [redacted] worked hard to ensure that my son and daughter received their electric Stair Lift this year. My son can now go UPSTAIRS to bathe in his bathtub without strain on himself or me. His sister can go down the stairs on the lift, when previously it was becoming very difficult for me to get her down stairs myself. This mobility aide is such a blessing; I cried when [redacted] told me that we were approved! Thank you, [redacted] We have also received respite hours, which are so priceless to me as a single parent Caregiver. [redacted] took the initiative to find wheelchair coats for both of my children who needed them. She has looked up toothbrushes for those with oral aversion/autism, bed liners so I don't have to wash my sheets as often, and diaper wraps to keep my children's skin dry and their sheets and wheelchairs dry.
- Respite, Katie beckett insurance and zoo and sensory club membership
- Respite, Mentoring, Daily Living Skills support
  Health club/Fitness training support
  CCOP
- Respite care.
- / child care
- social group and respite
- Respite, help with paying for the summer program and other sensory items purchased for our child.
- Help with supplies, respite care, equipment and resources.
- Respite care, sensory items
- Respite, equine therapy, crisis planning
- We haven't gotten alot of supports yet since our family is newer to the waiver, but when they get a spot in the social skills class, I feel that that will be a tremendous help for all of us. Respite is also in the process of setting up, but that will also likely be good for all of us, as a mental and emotional break will do us all good from time to time.
- Having respit hours that we can use anytime during the month that we need them.
- Respite
  Child care
  Sensory tools
- Daily living skills, respite care, [redacted] membership/programs, aquatic therapy, music therapy, personal training.
- Respite care
- Tuition for spec needs summer camp to be paid for. And our monthly respite & childcare & Mentor hours.
- Respite care. Resources for food. Needed purchases necessary during crisis medically homebound. Pool for recovery and [redacted] so helpful. Very hard to find service for Teens!!

- Theraputic support for parents.
  Respite care for parents
  Financial support to offset costs
- Family options therapy
  Respite care
  [redacted]
- Camp, respite, activities
- The Respite care and child care support, is the most helpful because that way as family we can take a little breaks.
- Child care assistance after age 12. Door alarms, memberships for social and learning activities.
- Repite and connections to the community with what options may be available.
- Respite care services through Broadscope.
- Respite.
- Respite care
- Respite, sensory items like weighted stuffed animal.

Gym Membership/Swim Lessons: (28)

- Our memberships to do safe activities, like We Rock the Spectrum
- We really appreciate the memberships to help support our family to be able to go out in the community and expose both of our special needs children to great experiences. We really appreciate the swimming lessons--they have been a very positive impact on our children's development. The services provided by the county has improved the quality of both of our children's lives and help support or family greatly.
- Respite, sensory gym, and a safety fence that will be installed this spring.
- Adapted swim, community pool pass, [redacted], wipes, zoo pass. We've never had anything else approved through Waukesha CLTS.
- The autism consultant we are working with is amazing. Swimming lessons and summer camp.
- Membership to the [redacted], adaptive swim at the [redacted] and equine therapy with [redacted] are services that have significantly impacted [redacted] improvements in speech and emotional regulation.
- Music and Swim
- Respite, Mentoring, Daily Living Skills support
  Health club/Fitness training support
  CCOP
- CCOP funding so we could get a gym membership to keep our kiddo healthy
- Swimming lessons.
- Swim lessons for safety, zoo pass for education and fun outings and pull ups and wipes for sanitary needs.
- Daily living skills, respite care, [redacted] membership/programs, aquatic therapy, music therapy, personal training.
- [redacted] membership, because it opens up so many opportunities for my daughter to be involved in.
- Birth to 3
  Future swim classes
- The special needs swim lessons.
- summer camps, music classes, horseback riding, art classes, [redacted] membership, [redacted]
- Use of the [redacted] for physical strength and activity.
- [redacted]
- Community and caregiver support, and 1:1 swimming lessons.
- Swim is definitely our favorite. It has helped our boy be more independent.
- The [redacted] program that my family has, the Y really gives my daughter a chance to get energy out, and do something that she enjoys.
- Family membership to the [redacted], which has been taken away.
- ABA and our [redacted] and swim lessons.
- A members to the YMCA so my daughter could go to get energy out, and we had a place to take her to do so
- Music therapy and strength training seem to be the most helpful so far.

- Having swimming lessons and yoga.
- [redacted] membership
  Mental Health counselor

Subscriptions/Memberships: (21)

- Physical therapy support items. Educational/social items like a zoo pass.
- Adapted swim, community pool pass, diapers, wipes, zoo pass. We've never had anything else approved through Waukesha CLTS.
- So far, [redacted] and my son's therapist.
- Respite, Katie beckett insurance and zoo and sensory club membership
- [redacted], DLS, Speech therapy
- Tools for home, activities through autism society. We have asked for other passes to join in public social spaces and classes to further support our child. We’re told that neither are supported in the program.
- Respite, help with paying for the summer program and other sensory items purchased for our child.
- Swim lessons for safety, zoo pass for education and fun outings and pull ups and wipes for sanitary needs.
- Adapted swim, community pool pass, diapers, wipes, zoo pass. We've never had anything else approved through Waukesha CLTS.

[redacted]

- [redacted] ,
- summer camps, music classes, horseback riding, art classes, [redacted] membership, Sensor Club
- Family options therapy
  Respite care
  [redacted]
- Medication insurance was very helpful. Specialized tutoring at Learning Rx helped our son tremendously.
- The bathroom wipes being provided. We were utilizing a membership at The Sensory Club.
- Child care assistance after age 12. Door alarms, memberships for social and learning activities.
- Lifestiders, the y membership and Journey 21 have been wonderful for our son.
- I have get only one program [redacted] and is being really helpful to [redacted].

[redacted]

Adaptive Aids/Special Supplies: (12)

- Tools for home, activities through autism society. We have asked for other passes to join in public social spaces and classes to further support our child. We’re told that neither are supported in the program.
- Adaptive equipment
- Respite, help with paying for the summer program and other sensory items purchased for our child.
- Respite care, sensory items
- Extra funding for sensory items.
- A goal was to get my daughter physically active and we are incredibly happy with the program with [redacted] We are also so grateful for the new [redacted] for my daughter as her old one was so old we couldn’t get her any new learning games and she had outgrown what was on her old iPad.
- Respite
  Child care
  Sensory tools
- Coping skills tools for my child and safety tools for child and parents.
- The extra curricular activities that are able to be provided so my children have an outlet. Or even the smallest thing like chewlry so break away the chewing habit.
- [redacted], helping to obtain an [redacted]. Supporting different ADHD support items so far.
- Respite, sensory items like weighted stuffed animal.
- Sensory items that I put through CTLS. Most I purchase with my own funds but while doing our review, the case manager asked if there was anything needed so the next item I was going to purchase for my child was brought up. It wasn’t expensive ($100) so she thought it could be covered. That was helpful to our family if 4

with one income. Looking forward to getting more information about social groups and the other things discussed during our review.

Service Coordinator: (11)

- Talking to my case manager to get support.
- Having someone who understands and helped with suggestions of needs my child needed. Provided helpful information and guidance as well.
- My daughter was offered services we didn't know existed but were exactly what she needed. Our coordinator has been amazing and connected with my daughter right away!
- Having someone in my corner to talk through things and get an unbiased opinion or direction. As parents we get very caught up in what we feel is best for our kids, but sometimes it's not.
- Being able to talk through our daughter's needs and issues and getting her much-needed services, which we would not have known about without the help of our coordinator.
- Being able to go to the Count Representative with specific questions based on my child's current struggles.
- Having the service coordinator check in regularly. The service coordinator suggesting things and ideas that could help.
- IRIS support (financial and otherwise) of our child's attendance at [redacted] in [redacted], a transition academy for the neurodivergent post-high school. All of the [redacted] we have had work with us have been great, showing genuine interest in our child's situation and interacting with us frequently and in particular always asking if we have any additional questions.
- Extracurricular activities that supported my son's needs. The check-in emails & face to face meetings were super helpful to discuss challenges in daily life.
- [redacted] She is AMAZING!! She is so responsive, so well connected, so responsive. She is an absolute God send to my family!
- Nothing has been done since my meeting with my hander.

Camp: (10)

- Summer camps and programs that are available.
- The autism consultant we are working with is amazing. Swimming lessons and summer camp.
- The therapies and camps that are covered - [redacted] music therapy, social skills and art therapy.
- [redacted] access and support as well as Amazon purchases.
- Tuition for spec needs summer camp to be paid for. And our monthly respite & childcare & Mentor hours.
- summer camps, music classes, horseback riding, art classes, YMCA membership, Sensor Club
- [redacted] camp
- Camp, respite, activities
- Summer Camp, getting a humidifier to help his breathing , his incontenice/ potty supplies
- Funding for summer camp, but it sounds like that won't be covered anymore.

Music & Art Therapy/Lessons: (10)

- Services to support skill development such as art and music therapies.
- Music and Swim
- The therapies and camps that are covered - [redacted]), music therapy, social skills and art therapy.
- The waiver program. Son was able to get enrolled in music therapy classes and daily living skills care giver that have greatly improved his communication skills.
- Daily living skills, respite care, [redacted] membership/programs, aquatic therapy, music therapy, personal training.
- The most helpful is the Music Theraphy that our son is getting and we really do appreciate that the program provide us some items to help our son to boost his skills and for some of the items to make him safe it really helps us a lot financially too since some of the items are very pricey.
- summer camps, music classes, horseback riding, art classes, [redacted] membership, [redacted]

- My child currently participates in music therapy, equine therapy, art therapy, and yoga/somatic therapy—We love each program and provider, we cannot possibly choose a favorite. My child has grown tremendously by being given access to these supports. Thank you!
- therapy sessions (art, music, and so on)
- Music therapy and strength training seem to be the most helpful so far.

Waiver/Program: (9)

- Finding financial assistance, providing information about specialized support and services.
- CLTS
- The waiver program. Son was able to get enrolled in music therapy classes and daily living skills care giver that have greatly improved his communication skills.
- The CLTS waiver program has allowed our son to access therapeutic services he may not have been able to receive and we are seeing tremendous benefits for him as a result of the programming.
- None as the Waukesha County CLTS Providers are most often "independent agencies" that are expensive with high turnover, no regard for child safety, and simply collecting tax dollars through the CLTS Program without true help for the family or child with disabilities.
- CTLS has been outstanding with knowing our sons needs and what items might be best for his sensory needs.
- All the the services and support we have received
- We primarily utilize the CLTS waivers program to help fund activities that are beneficial to our daughter's development.
- Every single service is helpful for my family.

Equine Therapy: (7)

- Membership to the [redacted], adaptive swim at the [redacted] and equine therapy with [redacted] are services that have significantly impacted [redacted] improvements in speech and emotional regulation.
- Respite, equine therapy, crisis planning
- equine therapy with LifeStriders, social skills group with [redacted], getting connected with services available through CCS
- [redacted] ,
- summer camps, music classes, horseback riding, art classes, [redacted] membership, [redacted]
- My child currently participates in music therapy, equine therapy, art therapy, and yoga/somatic therapy—We love each program and provider, we cannot possibly choose a favorite. My child has grown tremendously by being given access to these supports. Thank you!
- [redacted] have been wonderful for our son.

Home Modifications: (7)

- Respite, sensory gym, and a safety fence that will be installed this spring.
- Respite and child care and home modifications.
- worked hard to ensure that my son and daughter received their electric Stair Lift this year. My son can now go UPSTAIRS to bathe in his bathtub without strain on himself or me. His sister can go down the stairs on the lift, when previously it was becoming very difficult for me to get her down stairs myself. This mobility aide is such a blessing; I cried when [redacted] told me that we were approved! Thank you, [redacted] We have also received respite hours, which are so priceless to me as a single parent Caregiver. [redacted] took the initiative to find wheelchair coats for both of my children who needed them. She has looked up toothbrushes for those with oral aversion/autism, bed liners so I don't have to wash my sheets as often, and diaper wraps to keep my children's skin dry and their sheets and wheelchairs dry.
- Fence blocking road in yard due to child elopement.
- The waiver to assist in an adapted bathroom for my daughter.
- Bathroom remodel to make our shower/tub more accessable for our child. Little things like soap and tooth paste dispensers have really helped to build our child independence and confidence!
- We received an out door swing frame for our sons sensory needs after the oak tree in our yard had to be removed.

Safety Items: (6)

- The most helpful is the Music Theraphy that our son is getting and we really do appreciate that the program provide us some items to help our son to boost his skills and for some of the items to make him safe it really helps us a lot financially too since some of the items are very pricey.
- Coping skills tools for my child and safety tools for child and parents.
- Safety devices for our home to ensure our child's safety.
- Child care assistance after age 12. Door alarms, memberships for social and learning activities.
- ABA and [redacted] and swim lessons.
- Initially ABA therapy - I genuinely believe access to those services gave not only our child, but our whole family the support we needed to flourish. [redacted] for eloping and general safety concerns so we have peace of mind as our little one explores the world.

Diapers/Wipes: (6)

- The only thing we've CONSISTENTLY received in the last year were pull-ups.
- Adapted swim, community pool pass, diapers, wipes, zoo pass. We've never had anything else approved through Waukesha CLTS.
- Swim lessons for safety, zoo pass for education and fun outings and pull ups and wipes for sanitary needs.
- Wipes
- Summer Camp, getting a humidifier to help his breathing , his incontenice/ potty supplies
- The bathroom wipes being provided. We were utilizing a membership at [redacted].

Social Skills: (5)

- The therapies and camps that are covered - [redacted] music therapy, social skills and art therapy.
- social group and respite
- equine therapy with [redacted], social skills group with [redacted], getting connected with services available through CCS
- We haven't gotten alot of supports yet since our family is newer to the waiver, but when they get a spot in the social skills class, I feel that that will be a tremendous help for all of us. Respite is also in the process of setting up, but that will also likely be good for all of us, as a mental and emotional break will do us all good from time to time.
- [redacted] socialization classes

Daily Living Skills: (4)

- Respite, Mentoring, Daily Living Skills support
  Health club/Fitness training support
  CCOP
- [redacted], DLS, Speech therapy
- The waiver program. Son was able to get enrolled in music therapy classes and daily living skills care giver that have greatly improved his communication skills.
- Daily living skills, respite care, [redacted] membership/programs, aquatic therapy, music therapy, personal training.

Applied Behavior Analysis (ABA) Therapy: (3)

- The autism consultant we are working with is amazing. Swimming lessons and summer camp.
- ABA and our [redacted] and swim lessons.
- Initially ABA therapy - I genuinely believe access to those services gave not only our child, but our whole family the support we needed to flourish. [redacted] for eloping and general safety concerns so we have peace of mind as our little one explores the world.

Caregiver Support: (1)

- Community and caregiver support, and 1:1 swimming lessons.

Appendix C

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

Access to Providers/Services: (46)

- I would like to see more availability for ABA who were diagnosed later in life.
- Recreational development such as museum passes, swim lessons, etc.
- We were able to have our older son join martial arts through [redacted], but the state has now made it so difficult for the owner to continue their partnership, so we can no longer use the CTLS program for funding. This was EXTREMELY disappointing, since our kid finally has an interest in a sport that will help him both physically and socially.
- Communication, consistency in coordinators, [redacted] is HORRENDOUS and their communication is nonexistent.
- Ease of coordination between services & families. I wanted to start my son in an equine therapy and the service provider texted me 18 pages to complete, she did not respond to any questions I had and we decided not to have him use their services any longer. The coordinator quit, so she was unable to step in and assist. Ease of communication between coordinators and families.
- There are gaps when it comes to communication devices/supports. For example childs ipad was shattered at ABA and a replacement was not covered despite it being the child's only means of communication. Letter of medical necessities were written by BCBA and speech therapist.
- Contracts very limited
- My son has a rare genetic disorder called [redacted], epilepsy, he is autistic, and non-verbal. Measured as level 3 autism and severe IDD. We cannot find respite or caregiving services for my son. As his primary caregiver I am unable to care for my son and work as well, I am living off of savings. I live in constant fear of my savings running out as an unmarried special needs mom. I wish there were more supports and services offered to my son to help integrate him into the community as well as allow me to work and provide for the two of us. Or paid parent caregiving. I know my son best. He should be able to choose me as a caregiver, but I cannot survive as a caregiver without an income.
- The vendors for products are limited.
- It is very difficult to find and hire respite workers. It would be so wonderful to have a list of respite workers who are willing to be trained to care for a medically complex child/children. The pay for the respite workers could be better and more competitive.
- Providers are not properly understanding the kids from Child Support. They often treat special kids as regular kids and that is causing issues. Providers should have basic of knowledge of special kids before they are agreeing to take kids from child support.
- [redacted] (they dropped CLTS due to payment delays)
  [redacted] also dropped CLTS due to payment problems
- Not enough respite care. We are "given" 20 hours a week, and can barely get 10 most weeks, due to lack of resources.
- Clear definition of what is and is not included in the program We are told we could do things like martial arts, art therapy, and theater classes to grow our daughter’s social emotional skills. When we asked for classes we’re told none are available. Similar we asked for local passes to zoo and museum to build our daughter’s sensory experience and strengthen sibling relationships in a space outside the home. We are told this is not supported (but [redacted] supports this) We were told a membership for our daughter to our gym (or any gym) is not supported because she can’t use it independently. However, we were given a membership to a sensory gym. I asked for the family membership as goal was continue to develop relationships with siblings outside of the home. Case worker agreed, but then processed only single membership. When I sent back notes and asked siblings to be added was told I would have to wait for renewal in 6 months.
- The ability to use the [redacted] for a class is extremely frustrating. It is one of the few sports [redacted] likes and participates in, yet CLTS and [redacted] have an ineffective relationship.
- Navigating all the varying programs

- It feels as if there isn't much offered to help both of my elementary aged kids with an outlet for their energy or meeting other kids. The covered classes (swim) are wonderful, but they need something that allows for "free time or open play" and a chance to meet other kids, rather than structured like classes. More support or training for newer coordinators might be beneficial too. Our coordinator either seems extremely overworked/overwhelmed or perhaps not enough training, as our first few months in the program have been a little frustrating. There also seems to be a gap between information from the social worker and the coordinator. We were told some information during our intake, as far as coverage, that the coordinator is saying isn't possible.
- [redacted] was unable to provide a resource for my daughter most of the year. It would be helpful if the bill came itemized for what I am paying for. Thanks
- Transportation to ABA therapy is not covered (MTM is awful). JB Medical is awful - customer service is terrible …product is damaged or late, no one helps, people change stories …took us almost a year to get diapers.
- Communication has been terrible. We have been told one thing in an in person meeting and then something different after that. No consistency. Access to services has been minimal at best. Very disappointed in the services we've received. I've reached out to our case worker's supervisor and still did not receive a response.
- We need more art therapy providers.
- Finding therapist in a timely matter.
- The gaps in services and support relate to real-world services & supports for families. CCS is impossible to access due to a faulty Functional Evaluation that is entered solely by a Service Coordinator who has spent 5 minutes with the child with disabilities and fails to truly understand the gravity or metrics shared by the family. There are not enough in-home human supports or providers to teach daily living skills, board games, or any other real-world skills for children under age 13 in a play-based model. Most children are developmentally delayed cognitively and using software is not able to be generalized or taught by parents to the child with disabilities as it requires actual human intervention with humans educated on cognitive delays or intellectual disability. There is no participation funded for community sports due to Waukesha County leaders having zero knowledge in what "inclusion" means within each suburb community the child resides in. [redacted] should be fired due to [redacted] nature in communicating with families on CLTS - no one wants to hear about "all the ways" she allegedly tried to protect families on every single request she solely decides to decline requests for. [redacted] The term "recreation" needs to be dropped from all CLTS staff permanently as all sports & museums & memberships of any natures should be included as automatic request approvals due to the nature of THERAPEUTIC RECREATION having significant evidence & research on the impact for overall inclusion & independence with people with disabilities. Waukesha County CLTS staff should all be required to hear from WI BPDD self-advocates and Partners in Policymaking keynote speakers to learn exactly why they need to approve more requests within the same week the requests came in. CLTS is not tracking denials or the way Waukesha County likes to deny requests by ignoring them or not providing formal denial letters in hopes the family will forget or drop the request - data is likely to prove the disparity from Waukesha County and the entire state in how little children with disabilities are supported by CLTS or CCOP in Waukesha County. Waukesha County has hired too many service coordinators for no reason. Waukesha County has not received budget increases in years for CLTS despite 300% increase in participation, which proves [redacted] is not making appropriate decisions for children on CLTS. Service Coordinators are falsely reporting hours worked on each case per month on the ISP/ISFP - there is no service coordinator spending 5+ hours/month on any 1 child with disabilities. Family Parental Cost Share should not be required to pay for [redacted] or any other expensive financial provider as their fees are extremely high & inappropriate for software to perform minimal work. There is a huge gap in children with disabilities and literacy - health, self-advocacy, and general reading skills. CLTS should be required to include payment for tutors for reading with children who have intellectual disabilities as public schools will not pay for tutors & this population is extremely vulnerable long-term in communities and must learn how to read by any & all means necessary. CLTS pays for [redacted] and [redacted] which are licensed as Tutors as well as CLTS PRoviders and this means reading tutors can easily be covered for children with cognitive & intellectual development delays/disabilities.

- Medical supplies that me need like diapers.
- I really hope that the Music therapist is not changing every six months since our kid is needs some time to connect and interact with other person and once he’s already connected, what happened was the therapist needs to be changed so it’s really hard because sometimes he doesn’t wanna do anything because he’s still in the stage of knowing and building trust to the therapist.
- Not knowing the exact quality and compatibility of particular service providers because they there was no standardized comparison tool. I wish there was a way to give feedback on providers and improve services for all parents.
- Summer camps and funding for siblings
- Service coordinator turnover, reduction in CCOP funding, confusion about eligible or conflicting services, etc.
- Availability of respite and independent living providers willing to come to the western part of Waukesha County.
- Could not figure out how to get Goodnight pullups covered. (probably more on my but not an easy process)
- I’m unsure of the delay for one our new providers. Have been following up weekly.
- In child care they make to many requirements, and in my opinion in my position as a mom I need to have the flexibility to choose the best for my kid. Also more resources for private for example swimming clases, pneumonia of the places is [redacted] and they lack in customer service support.
- We never received any music therapy that was originally offered. The same is true about in home help with self care We would LOVE it if swimming lessons were covered since a majority of autistic children are drawn to water.
- It is complicated to get on board some providers.
- I wish there were more play place options for getting out energy and being able to be social.
- It would be nice if there was a brochure or site that would identify all of the possibilities and services that may be available to our children.
- It is very hard to find respite care.
- YES! Receiving information that was discussed at meetings and via emails for additional support.
  Things that are already listed on the ISP that are covered by CLTS shouldn't require approval every time my child needs to register for things like swimming. Do to the long process of getting approved every 8 weeks, my child has missed being able to register for swimming lessons at the [redacted] several times, essentially not being able to continue learning how to swim and be safe around water. Getting approved for swimming lessons is a long exhausting process, that quite honestly I gave up on.
- The hardest part sometimes is waiting for [redacted] to approve new empoyees. Having respite is critical to making sure we are able to make appointments for our other children.
- My daughter doesn’t know what she needs, unless you don’t work or have a significant other, no services will happen, you have to do the leg work, at times when I’m working, single parents, still getting brunt end of the stick.
- Mental/behavioral health support and actual enrollment to support programs themselves would be more helpful. We have not actually gotten much outside of the insurance support with Katie Beckett. I've been given names of providers with minimal success getting into programs.
- Understanding how the program works and what is eligible for funding, having staff who have the time/capacity to work with families. Also, we desperately want him to attend summer camp not for childcare but because he's in need of the routine and structure and we haven't been able to get an answer on what was covered. I also know that different kids have different needs, but certain purchases we were told were considered regular parenting expenses other families have had covered- while I understand they could have different needs, it doesn't seem like there's consistency among what qualifies as a regular parenting expense.
- We don’t know what’s out there. Feels a lot of the burden is on the family to find a resource and then wait to see if it’s approved
- I think the equipment needs for kids with mental health needs seems narrow in scope.
- It’s hard to find good mental health dr’s that are taking new patients.
- The lack of places to get respite care from.

None/No Gaps: (41)

- As of right now, there is not many gaps from our needs to what is appropriate to provide.
- No
- Nothing I can think of now.
- N/A
- None
- None
- Not sure
- No
- N/A
- No
- No
- None
- None. I am forever thankful for the services available.
- No
- N/A
- NA
- Not particularly.
- We do not have any gaps to report.
- I have been happy with the services offered.
- No
- Na
- None that I have seen
- N/A
- I have not experienced any. [redacted] has been wonderful and always responds very quickly. She has always been available when I have needed her.
- We don't have any at this time.
- none that I can think of
- no
- None right now
- No
- None
- None
- None
- No
- no
- I don't really see anything.
- No
- None at this time.
- None
- No
- No
- No

Service Coordination: (28)

- We changed workers about 3 times in one year, that can create some lag.
- Communication, consistency in coordinators, [redacted] is HORRENDOUS and their communication is nonexistent.
- Ease of coordination between services & families. I wanted to start my son in an equine therapy and the service provider texted me 18 pages to complete, she did not respond to any questions I had and we decided not to have him use their services any longer. The coordinator quit, so she was unable to step in and assist. Ease of communication between coordinators and families.
- No respond from new social worker.
- We have been very happy with the help of our service coordinator.
- There is little to no follow through in offers of support, taking months to get anything at all taken care of.
- Not everything qualify for approval
- Turnaround with staff. Timing to receive benefits and unclear what's all available. I find out more from other families than service coordinator.
- It seems there is a lot of turnover with the staff. We've probably had three coordinators in three years. Some better than others.
- /timely response from the coordinator
  /No response from the coordinator
  /Coordinator not responding
- Our service coordinator left her job toward the end of the year, so it was and still is difficult switching to a new one. Communication wasn't the greatest during the transition.
- Our coordinator is great but we still have to do all the legwork. It becomes overwhelming at times.
- So many changes in people.
- It seemed like our service coordinator tried to find ways to make the process difficult and to say no. She also had little respect for our schedule and would often require meetings with very little notice.
- Getting respite care, constant changes in case manager (we had 3 different ones this past year) that required redoing our paperwork and information each time - didn't seem like previous information carried over to new case manager, case manager does not seem to be very proactive in offering solutions/services, case manager does not always seem to know what's available to meet our child's goals
- It feels as if there isn't much offered to help both of my elementary aged kids with an outlet for their energy or meeting other kids. The covered classes (swim) are wonderful, but they need something that allows for "free time or open play" and a chance to meet other kids, rather than structured like classes. More support or training for newer coordinators might be beneficial too. Our coordinator either seems extremely overworked/overwhelmed or perhaps not enough training, as our first few months in the program have been a little frustrating. There also seems to be a gap between information from the social worker and the coordinator. We were told some information during our intake, as far as coverage, that the coordinator is saying isn't possible.
- Too much staff turn over. It seems like just when we get used to someone, they leave or we are reassigned.
- Communication has been terrible. We have been told one thing in an in person meeting and then something different after that. No consistency. Access to services has been minimal at best. Very disappointed in the services we've received. I've reached out to our case worker's supervisor and still did not receive a response.
- The response time from our coordinator. I wait weeks for a response and have to usually send at least another email to f/u to my original email. One of my son's therapist had reached out to her also in the past and never had a response back. I'm not sure what the turn around time frame is to be expected or what is the "norm".
- The gaps in services and support relate to real-world services & supports for families. CCS is impossible to access due to a faulty Functional Evaluation that is entered solely by a Service Coordinator who has spent 5 minutes with the child with disabilities and fails to truly understand the gravity or metrics shared by the family. There are not enough in-home human supports or providers to teach daily living skills, board games, or any other real-world skills for children under age 13 in a play-based model. Most children are developmentally delayed cognitively and using software is not able to be generalized or taught by parents to the child with disabilities as it requires actual human intervention with humans educated on cognitive delays

or intellectual disability. There is no participation funded for community sports due to Waukesha County leaders having zero knowledge in what "inclusion" means within each suburb community the child resides in. [redacted] should be fired due to her [redacted] in communicating with families on CLTS - no one wants to hear about "all the ways" she allegedly tried to protect families on every single request she solely decides to decline requests for. [redacted] The term "recreation" needs to be dropped from all CLTS staff permanently as all sports & museums & memberships of any natures should be included as automatic request approvals due to the nature of THERAPEUTIC RECREATION having significant evidence & research on the impact for overall inclusion & independence with people with disabilities. Waukesha County CLTS staff should all be required to hear from WI BPDD self-advocates and Partners in Policymaking keynote speakers to learn exactly why they need to approve more requests within the same week the requests came in. CLTS is not tracking denials or the way Waukesha County likes to deny requests by ignoring them or not providing formal denial letters in hopes the family will forget or drop the request - data is likely to prove the disparity from Waukesha County and the entire state in how little children with disabilities are supported by CLTS or CCOP in Waukesha County. Waukesha County has hired too many service coordinators for no reason. Waukesha County has not received budget increases in years for CLTS despite 300% increase in participation, which proves [redacted] is not making appropriate decisions for children on CLTS. Service Coordinators are falsely reporting hours worked on each case per month on the ISP/ISFP - there is no service coordinator spending 5+ hours/month on any 1 child with disabilities. Family Parental Cost Share should not be required to pay for Broadscope or any other expensive financial provider as their fees are extremely high & inappropriate for software to perform minimal work. There is a huge gap in children with disabilities and literacy - health, self-advocacy, and general reading skills. CLTS should be required to include payment for tutors for reading with children who have intellectual disabilities as public schools will not pay for tutors & this population is extremely vulnerable long-term in communities and must learn how to read by any & all means necessary. CLTS pays for [redacted], which are licensed as Tutors as well as CLTS PRoviders and this means reading tutors can easily be covered for children with cognitive & intellectual development delays/disabilities.

- I have been blessed with a good worker, who follows up and cares!! TY!!
- Service coordinator turnover, reduction in CCOP funding, confusion about eligible or conflicting services, etc.
- Some time when the social worker is to leave. [redacted] has a very hard time meeting anyone knew. Sometimes it is to much time for [redacted] to think about anyone knew in his life. [redacted] does not , like any thing new.
- Often times our point of contact would not respond for weeks or months and repeat emails would not be addressed with no explanation. If they were unavailable a point of contact should have been forwarded to another person.
- Having consistently different coordinators (however, I completely understand why this occurs).
- Small gap as we transitioned from one coordinator to another.
- Turnover in service coordination, we’ve had 3 different staff so we basically just had to redo ISP 3x.
- Our family was bounced around to several different case managers who knew we were a temporary responsibility and it showed through their efforts and time and attention given to Our family was bounced around to several different case managers who knew we were a temporary responsibility and it showed through their efforts and time and attention given to my concerns.

Misc./Other: (14)

- When a new year starts, continuing with services we previously had in place and sometimes have some small gaps.
- Limiting everything that is considered a “restraint” Some things are approved by doctors and therapists and they agree necessary for safety. While I realize the restriction is there to prevent any abuse, sometimes safety concerns are valid for a child to is severely disabled. When your body is the size of a 12 year old but your mind is 18month old you need safety preventions like a 18 month old. A special needs bed for example is not the same as tying a person down.
- Having one Dept say go to the waiver program they can take care of that. And feeling like you are then asking for to much from the waiver program. Our waiver worker os AWESOME

- The billing of birth to 3 was a little bit confusing at first but once we got it figured out it was smooth sailing.
- Broader options for co-op
- I would suggest a broader range of items that can be used for co-op
- Occasional issues with knowing the correct person to contact in regards to a specific answer. Typically quickly resolved.
- Guidance
- As simple as having a SPECIFIC Goal plan laid out for the upcoming year with the ability to modify if and when needed and a FOLLOW THROUGH process in place for both Parents and the Agency.
- Communication
- Ourselves
- There is no support
- time
- Not sure

Waiting for Services: (10)

- In the beginning there was a 6 month gap between when we officially applied and when we started the therapy. So our son is behind.
- Time. Mostly, we have been waiting for a pretty long time. However, I think that needs are immediate.
- Programs have very long waiting times.
- There seems to be a long time getting services approved and starting programs, especially when the contact person at CLTS changes during that time.
- The wait is always difficult. When our child qualified for CLTS and CCS it was because things had gone to a horrible level and her needs were extremely high. You don't qualify because the needs are low.
- The only thing we ever encountered was a long "wait list," but this was not the fault of the program but more of a "limited" amount of programs for mental health of children.
- waiting waiting and waiting. Timely manner problem.
- Not that this is a CLTS problem or that there's anything that they can do about it but the waitlists for most places are just insanely long. Our case worker will recommend therapeutic activities/programs, I'll look into them and get on the waitlist, and it'll be 2 years or more before some of these programs get back to us, if they do at all .
- Waiting lists.
- There can be a long wait to begin any types of services, especially just getting started.

Parental Payment Limit: (2)

- [redacted] was unable to provide a resource for my daughter most of the year. It would be helpful if the bill came itemized for what I am paying for. Thanks
- The gaps in services and support relate to real-world services & supports for families. CCS is impossible to access due to a faulty Functional Evaluation that is entered solely by a Service Coordinator who has spent 5 minutes with the child with disabilities and fails to truly understand the gravity or metrics shared by the family. There are not enough in-home human supports or providers to teach daily living skills, board games, or any other real-world skills for children under age 13 in a play-based model. Most children are developmentally delayed cognitively and using software is not able to be generalized or taught by parents to the child with disabilities as it requires actual human intervention with humans educated on cognitive delays or intellectual disability. There is no participation funded for community sports due to Waukesha County leaders having zero knowledge in what "inclusion" means within each suburb community the child resides in. [redacted] should be fired due to her [redacted] in communicating with families on CLTS - no one wants to hear about "all the ways" she allegedly tried to protect families on every single request she solely decides to decline requests for. [redacted]. The term "recreation" needs to be dropped from all CLTS staff permanently as all sports & museums & memberships of any natures should be included as automatic request approvals due to the nature of THERAPEUTIC RECREATION having

significant evidence & research on the impact for overall inclusion & independence with people with disabilities. Waukesha County CLTS staff should all be required to hear from WI BPDD self-advocates and Partners in Policymaking keynote speakers to learn exactly why they need to approve more requests within the same week the requests came in. CLTS is not tracking denials or the way Waukesha County likes to deny requests by ignoring them or not providing formal denial letters in hopes the family will forget or drop the request - data is likely to prove the disparity from Waukesha County and the entire state in how little children with disabilities are supported by CLTS or CCOP in Waukesha County. Waukesha County has hired too many service coordinators for no reason. Waukesha County has not received budget increases in years for CLTS despite 300% increase in participation, which proves [redacted] is not making appropriate decisions for children on CLTS. Service Coordinators are falsely reporting hours worked on each case per month on the ISP/ISFP - there is no service coordinator spending 5+ hours/month on any 1 child with disabilities. Family Parental Cost Share should not be required to pay for Broadscope or any other expensive financial provider as their fees are extremely high & inappropriate for software to perform minimal work. There is a huge gap in children with disabilities and literacy - health, self-advocacy, and general reading skills. CLTS should be required to include payment for tutors for reading with children who have intellectual disabilities as public schools will not pay for tutors & this population is extremely vulnerable long-term in communities and must learn how to read by any & all means necessary. CLTS pays for [redacted] [redacted], which are licensed as Tutors as well as CLTS PRoviders and this means reading tutors can easily be covered for children with cognitive & intellectual development delays/disabilities.

Children's Community Options Program (CCOP) Funding: (1)

- Service coordinator turnover, reduction in CCOP funding, confusion about eligible or conflicting services, etc.