

2022

Children with Special Needs

Consumer Quality Assurance Survey Report



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Executive Summary

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

The CSN Consumer Quality Assurance Survey is part of an ongoing commitment to continuous improvement and quality service. The survey consists of a questionnaire that was developed as a means of gathering feedback from the families we serve. Department of Health and Human Services 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.

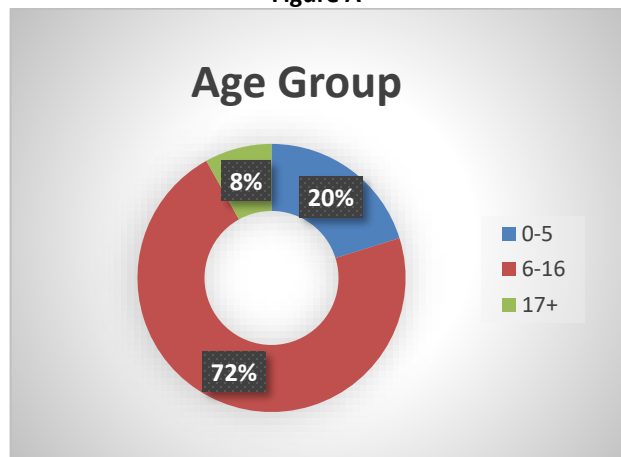
The Children’s Community Options Advisory Committee (formerly known as the Special Services Advisory Committee) has been instrumental in the annual success of this survey. The results of this survey are reviewed annually with committee members for further discussion and recommendations as to the prioritization of possible program enhancements. We encourage participation in the committee by the caregivers of any youth enrolled in the program, members of the community, and service providers who serve youth in addition to voting committee members as we value the opinions of all whose lives are impacted by an individual with a special health care need. CCOP Advisory Committee meeting dates, times, and agendas can be found at the following location: <https://www.waukeshacounty.gov/meetings/childrens-community-options-program-ccop/>

Survey administration began in 2016. In 2017-2020 a data analytics group compiled and analyzed the results. HHS mails the annual survey to the caregivers of every child who received services from the CSN unit within that calendar year. If a family has more than one child involved in CSN program, they received a unique survey for each 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, 2022.”*

A total of 99 caregivers responded to the age group question, with the findings shown in **Figure A**. Most caregivers (71) reported their child was in the 6-16 age group, (20) indicated their child was aged 0-5, and (8) said their child was 17+.

Figure A

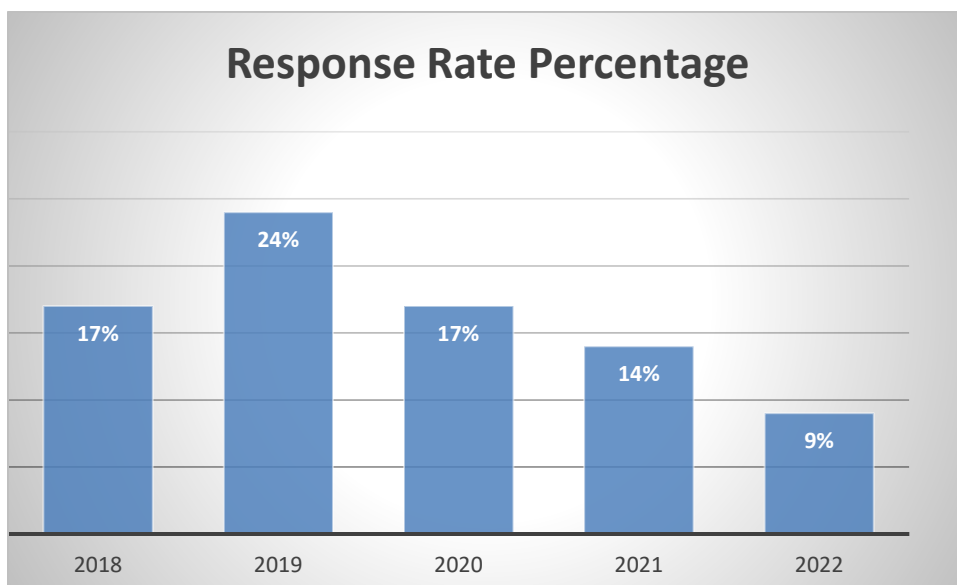


The survey consists of three sections. The Service Coordination and Program Specific sections include 13 statements which caregivers are asked to rate each statement on a 5-point scale: strongly disagree (1), disagree (2), neutral (3), agree (4) and strongly agree (5). The General Comments section provides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

In 2022, 1080 paper surveys were sent to valid parent/guardian addresses, and 101 completed surveys were returned. **Figure B** captures the response rate from 2018-2022. This year's response rate declined. This is a consistent trend with paper surveys within HHS. Efforts are being made to offer feedback opportunities to consumers in electronic format to increase response rates.

The 2023 CCOP Advisory Committee is committed to helping enhance the services received by those enrolled in Children with Special Needs programming. With their guidance, the 2023 Quality Assurance Survey will transition to an electronic survey with the use of QR Code to gain access. This year families will be notified of this change via a letter sent to the home.

Figure B



Major Findings

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

- Aggregate satisfaction with multiple dimensions of service coordinator performance remains above average and relatively stable over time.
- Service coordination and program outcomes are areas of strength, while the transition to adult services and the waiting for services are areas for improvement.
- Perceived self-involvement in service plan development/outcomes remains high, with 97% of caregivers endorsing “Strongly agree” or “Agree.” (Q1)
- Average levels of satisfaction with service coordination have decreased in terms of providing useful feedback, information, and resources (Q2); increased understanding of the program (Q3); timely response to requests, questions and concerns (Q4); follow-through with requests, questions and concerns (Q5); assisting with meeting the needs of the child and family (Q6); and amount of time available (Q7). Many of these questions decreased by two tenths of a point, however all of the response rates for each of these questions remain above the “Agree” rating.
- Most caregivers (65%) 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, 2021. However, survey responses (Q8) decreased for the fifth year in a row indicating families felt less supported by the service coordinator with this transition. There was some improvement in survey responses (Q9) since last year showing families felt more prepared for the transition to adult services.
- The percentage of caregivers indicating that their child experienced severe health and/or safety concerns while waiting for services decreased since last year (Q10). However, only half of the families (52%) felt that they were able to address their child’s needs while waiting to receive services (Q10a).
- The proportion of caregivers indicating that the program served to improve overall day-to-day functioning (Q11) and to support goal achievement (Q12) decreased from the previous year. The response in the “Strongly agree” and “Agree” categories decreased (Q11) from 81% in 2021 to 69% in 2022 and (Q12) from 78% in 2021 to 60% in 2022.

Program and Practice Adjustments

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

- Question 9 on Page 14, states, “My child was 17 years old as of July 1st, 2021; I feel that as a family we are prepared for the transition to adult services”. Last year’s average response dropped to our lowest overall survey response of 3 – Neutral. This year’s average response increased to 3.2 – just above Neutral. To continue improving the transition to adult services progression for our youth and families, the CSN leadership team joined in partnership with the Aging and Disability Resource Center (ADRC) in providing a 2-hour educational presentation in January 2023 for service coordinators to better understand the process and resources available to youth and their families during this time of transition. We also partnered with the ADRC to provide quarterly Youth Transition Presentations which rotate between in person and virtual attendance. These presentations provide education for the youth transition to adult services as well as a highlighted educational guest speaker. The ADRC also has a 32-page transition guide to assist families in the process. Transition resources can be found at: <https://www.waukeshacounty.gov/ADRC/>.

- In 2022, the Children with Special Needs Program experienced a significant amount of growth and change which conceivably could be associated with the decrease in scores on average by two tenths of a point. The following changes occurred:
 - The Medicaid Home and Community-Based Services (HCBS) Waiver Manual was updated with the 5-year Federal Medicaid Renewal cycle. The update enhanced the service array available by adding seven new service categories and renamed six service types. This resulted in a significant amount of administrative changes to support these service expansions.
 - Waukesha County Health and Human Services contracted with a second agency to provide support and service coordination. This agency had prior experience providing case management to government organizations, however, did not have prior expertise in the area of CLTS Waiver services. Therefore, extra preparations and training were implemented to ensure successful integration of the second agency to the Children with Special Needs program.
 - A substantial effort was placed on the hiring and onboarding 28 new staff in 2022. Due to the complexities of the program, it takes several months for service coordinators to learn all aspects of the job duties. It is plausible that the learning curve for new service coordinators has impacted the 2022 survey results.

The Children with Special Needs program is dedicated to enhancing the delivery of services to youth with special health care needs in Waukesha County. Our program staffing capacity has increased by 287% over the last five years to a team of 58 positions in 2023 serving over 1,300 youth. Based on this significant growth, in 2022 we revised the onboarding and training protocols, created a specific Children's Intake team and supervisor dedicated to streamlining eligibility and enrollment of new participants, created a no wrong door intake model for youth accessing all programs which use the Functional Screen as an eligibility tool, and added a Quality Assurance social work position to assure that we are following the State and Federal mandates of the program.

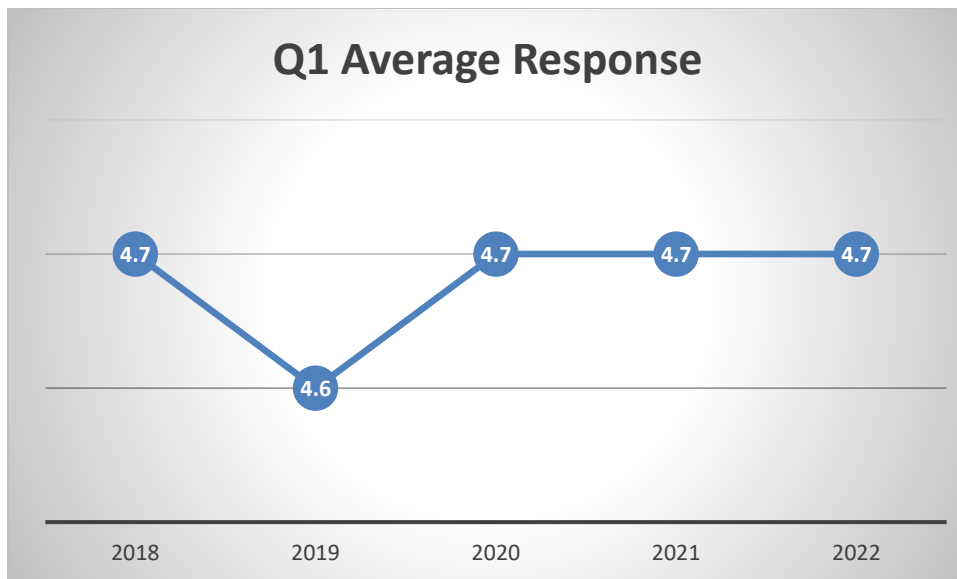
In 2023, we look forward to expanding our marketing materials with new brochures, an updated internet page, and a provider directory. Another focus is continued workforce education on community resources for families as well as cross divisional training on department programming available to families. An analysis and programmatic restructure of the Children's Community Options Program to be more efficient and to automate operations is also underway. And most importantly, the elimination of the long-standing waitlist and the transition to continuous enrollment into the Children's Long Term Support Waiver Program continues to be a priority. We are very pleased to note that as of March 2023, all youth have been assigned a service coordinator to provide services therefore eliminating the waitlist.

Service Coordination Results

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

Figure 1 shows that the average response (4.7) was closest to “strongly agree,” and this is the fourth time in five years that the average response was 4.7. A total of 97 caregivers (97%) selected “agree” or “strongly agree” in 2022.

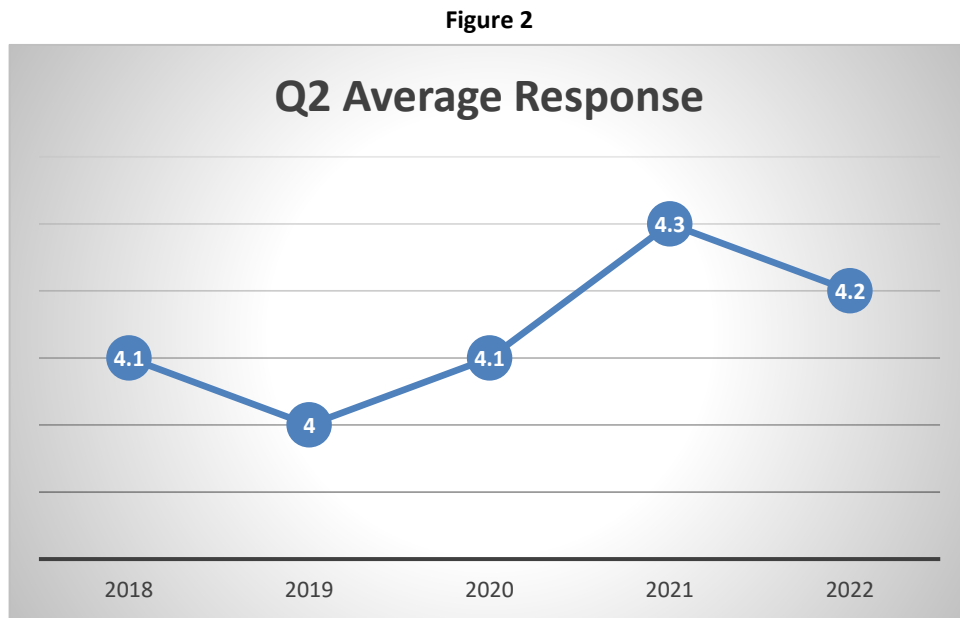
Figure 1



Q1	2018	2019	2020	2021	2022
Strongly Agree	104	106	86	85	72
Agree	34	31	23	24	25
Neutral	4	5	3	1	2
Disagree	1	1	0	1	1
Strongly Disagree	1	3	1	0	0
n=	144	146	113	111	100

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 (4.2) is closest to “agree”, and this response rate has decreased slightly from the previous year. A total of 82 caregivers (83%) selected “agree” or “strongly agree” in 2022.

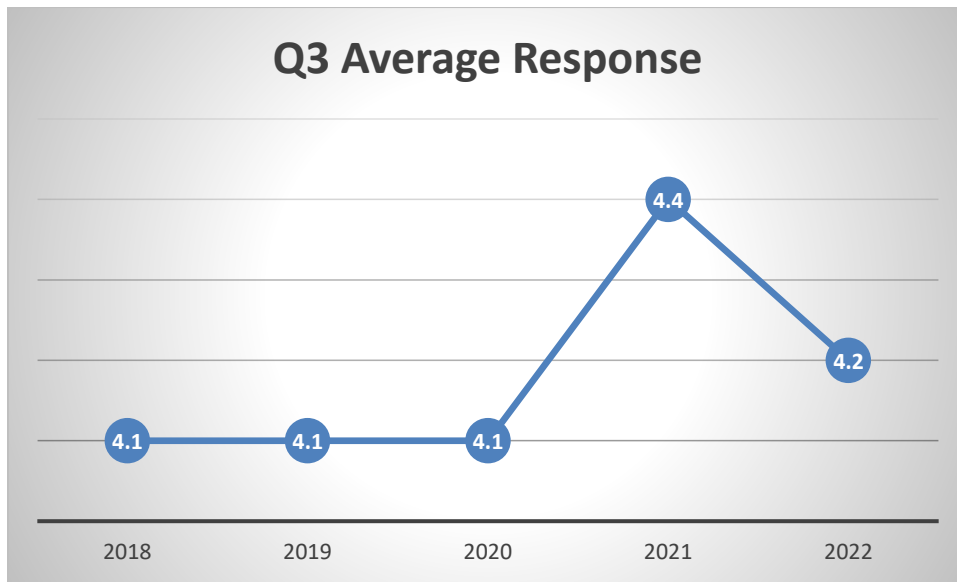


Q2	2018	2019	2020	2021	2022
Strongly Agree	59	63	50	60	48
Agree	52	49	39	34	34
Neutral	22	17	18	9	12
Disagree	6	11	4	7	2
Strongly Disagree	4	6	3	2	3
n=	143	146	114	112	99

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 (4.2) is closest to “agree”, and that the average level of agreement has decreased from the previous year. A total of 83 caregivers (83%) selected “agree” or “strongly agree” in 2022.

Figure 3

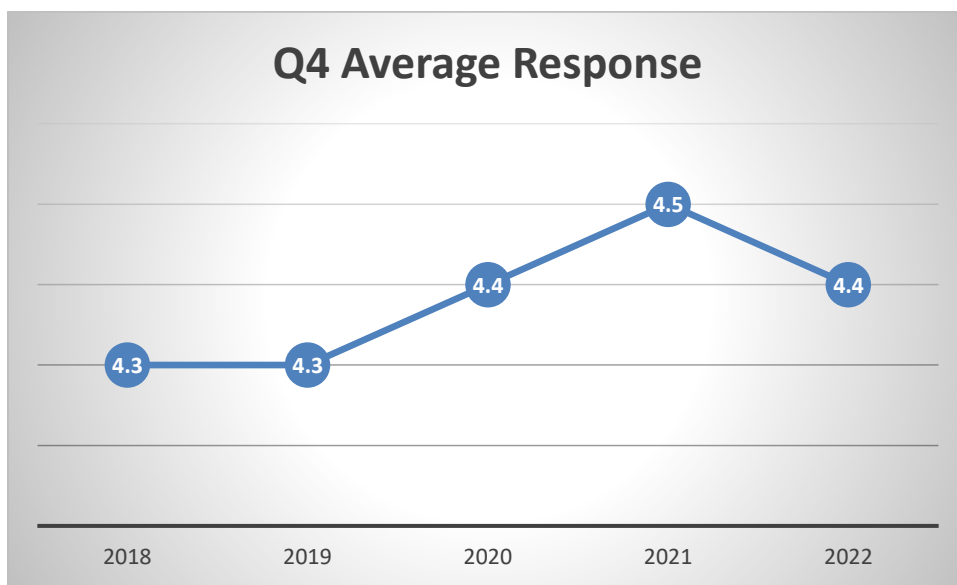


Q3	2018	2019	2020	2021	2022
Strongly Agree	66	68	48	68	49
Agree	43	47	47	29	34
Neutral	18	15	7	10	10
Disagree	12	5	7	4	1
Strongly Disagree	4	10	4	1	6
n=	143	145	113	112	100

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

Figure 4 shows that the average response (4.4) is between “agree” and “strongly agree.” The average level of agreement with this statement has decreased slightly from the previous year. A total of 87 caregivers (87%) selected “agree” or “strongly agree” in 2022.

Figure 4

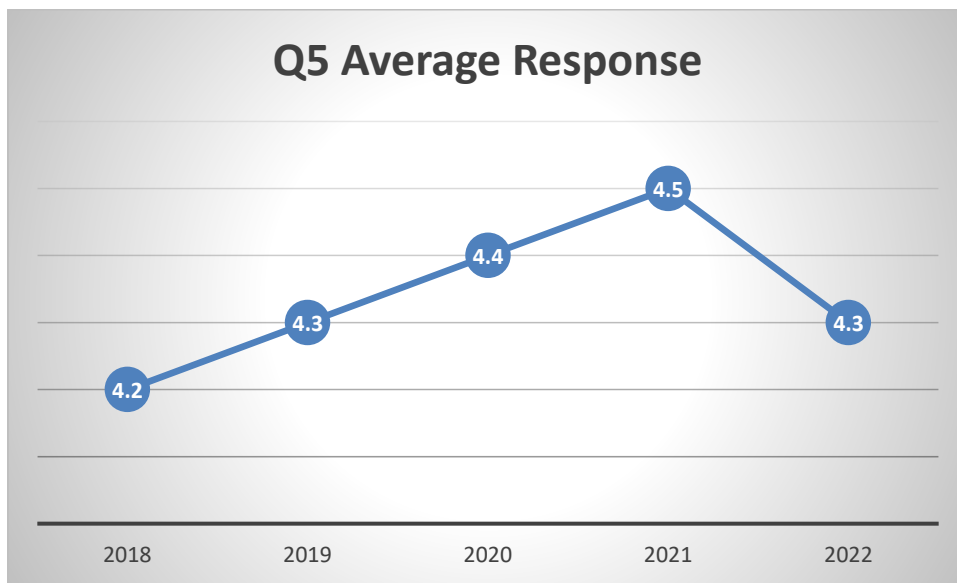


Q4	2018	2019	2020	2021	2022
Strongly Agree	76	82	65	71	59
Agree	42	35	35	30	28
Neutral	14	15	5	5	6
Disagree	6	9	5	2	4
Strongly Disagree	4	4	3	3	3
n=	142	145	113	111	100

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

Figure 5 shows that the average response (4.3) is between “agree” and “strongly agree.” Response to this statement has decreased from the previous year. A total of 84 caregivers (85%) selected “agree” or “strongly agree” in 2022.

Figure 5

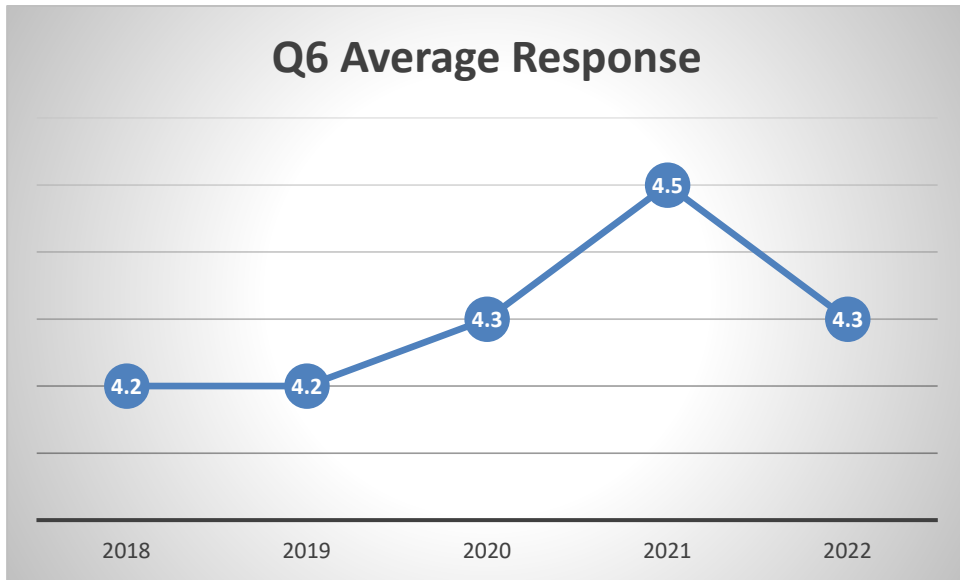


Q5	2018	2019	2020	2021	2022
Strongly Agree	74	78	67	68	56
Agree	43	40	30	36	28
Neutral	14	17	11	5	8
Disagree	10	6	3	0	5
Strongly Disagree	2	4	3	2	2
n=	143	145	114	111	99

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

Figure 6 shows the average response (4.3) is between “agree” and “strongly agree.” The average level of agreement has decreased from the previous year. A total of 88 caregivers (89%) selected “agree” or “strongly agree” in 2022.

Figure 6

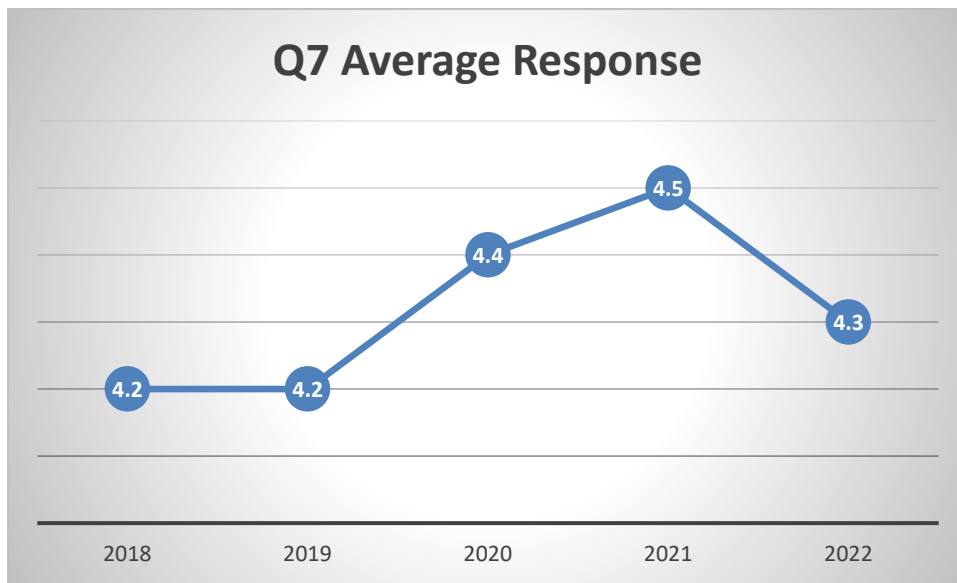


Q6	2018	2019	2020	2021	2022
Strongly Agree	78	72	63	68	48
Agree	35	45	36	36	40
Neutral	17	21	7	5	6
Disagree	8	4	1	0	1
Strongly Disagree	4	5	5	2	4
n=	142	147	112	111	99

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

Figure 7 shows that the average response (4.3) is between “agree” and “strongly agree.” The average level of agreement with this statement has decreased from the previous year. A total of 85 caregivers (86%) selected “agree” or “strongly agree” in 2022.

Figure 7

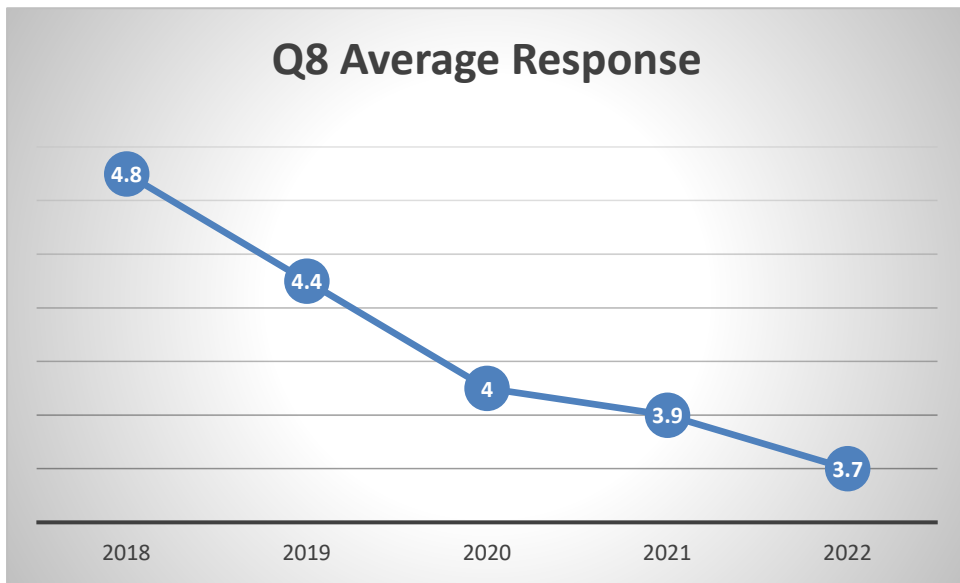


Q7	2018	2019	2020	2021	2022
Strongly Agree	77	74	67	71	50
Agree	35	48	37	30	35
Neutral	21	14	6	7	8
Disagree	5	5	1	2	5
Strongly Disagree	4	6	3	2	1
n=	142	147	114	112	99

Question 8:*[My child was 17 years old as of July 1st, 2021] My service coordinator has provided me assistance with the transition to adult services process.*

Figure 8 shows that the average response to this item (3.7) is closest to “agree”, and his represents a decrease in sentiment that has persisted for five years. Note the total number of caregiver responses to this question was 17.

Figure 8

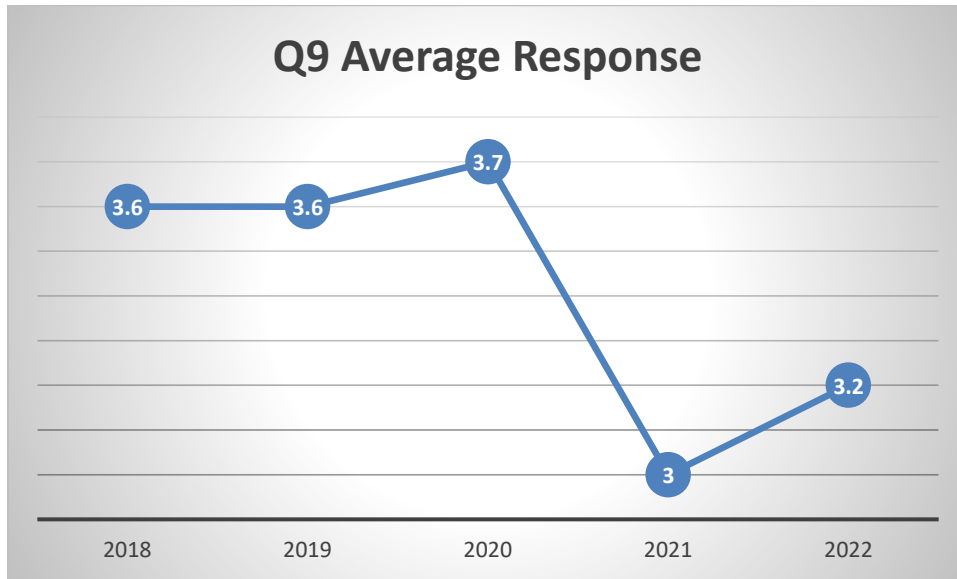


Q8	2018	2019	2020	2021	2022
Strongly Agree	8	4	2	6	7
Agree	2	2	1	3	4
Neutral	0	1	0	1	3
Disagree	0	0	1	0	0
Strongly Disagree	0	0	0	2	3
n=	10	7	4	12	17

Question 9: “[My child was 17 years old as of July 1st, 2021] I feel that as a family we are prepared for the transition to adult services.”

Figure 9 shows that the average response (3.2) is between “neutral” and “agree”, and the average response has increased since the previous year. Note that total number of caregiver responses to this question was 13.

Figure 9

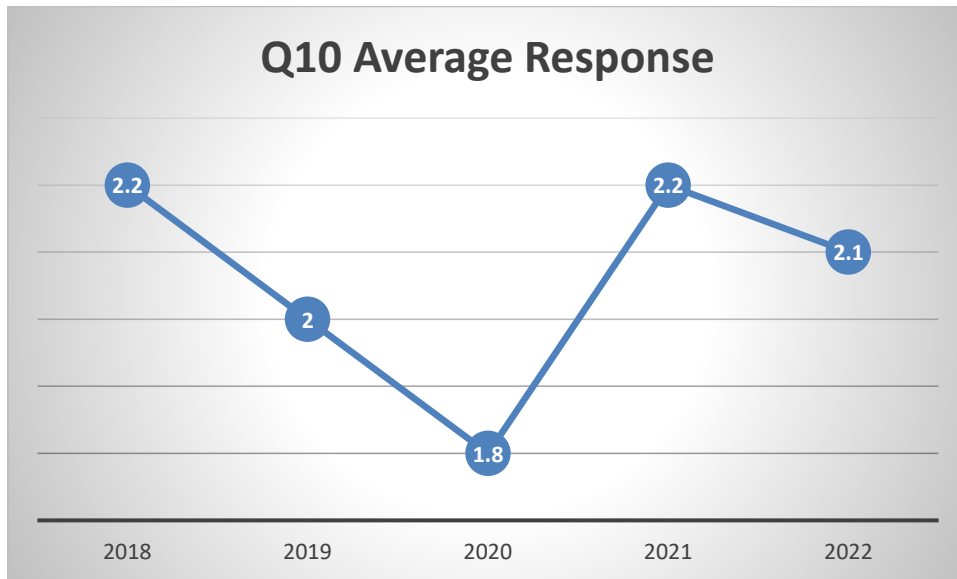


Q9	2018	2019	2020	2021	2022
Strongly Agree	2	3	3	1	3
Agree	4	4	2	3	2
Neutral	2	2	2	0	5
Disagree	2	1	2	1	1
Strongly Disagree	0	0	0	2	2
n=	10	10	9	7	13

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 (2.1) is closest to “disagree”, and that the level of agreement with this statement decreased since the previous year, indicating slight improvement in this response. Of the 91 responses, 74 (81%) endorsed responses of “neutral,” “disagree” or “strongly disagree” which indicates their child did not experience extreme health or safety concerns while waiting for services.

Figure 10

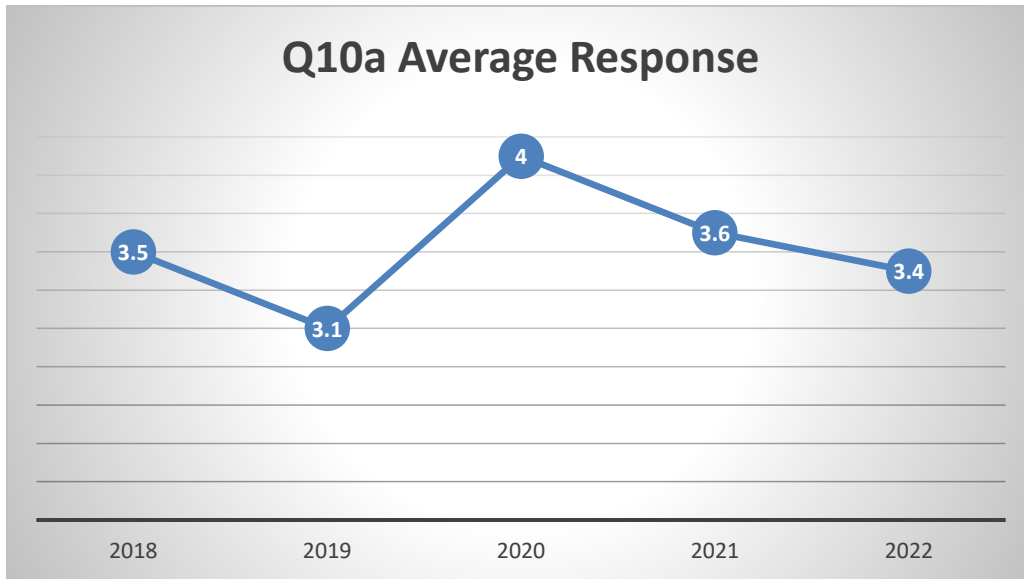


Q10	2018	2019	2020	2021	2022
Strongly Agree	11	10	10	10	7
Agree	10	11	2	12	10
Neutral	19	19	12	12	14
Disagree	32	29	22	19	16
Strongly Disagree	52	67	64	46	44
n=	124	136	110	99	91

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 (3.4) is between “neutral” and “agree.” The average level of agreement with this statement has decreased from the previous year. Note that total number of responses to this question was 23.

Figure 10a

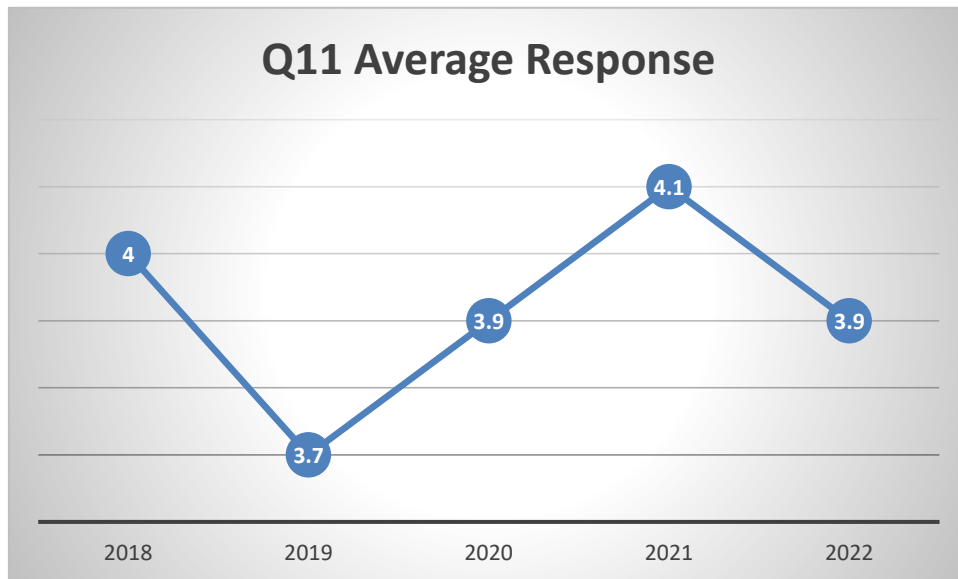


Q10a	2018	2019	2020	2021	2022
Strongly Agree	4	3	6	5	6
Agree	7	4	2	6	6
Neutral	6	3	2	4	5
Disagree	3	4	2	1	4
Strongly Disagree	1	2	0	2	2
n=	21	16	12	18	23

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

Figure 11 shows that the average response (3.9) is closest to “agree”, and that the level of agreement with this statement decreased since the previous year. A total of 66 of the caregivers (69%) endorsed “agree” or “strongly agree.”

Figure 11

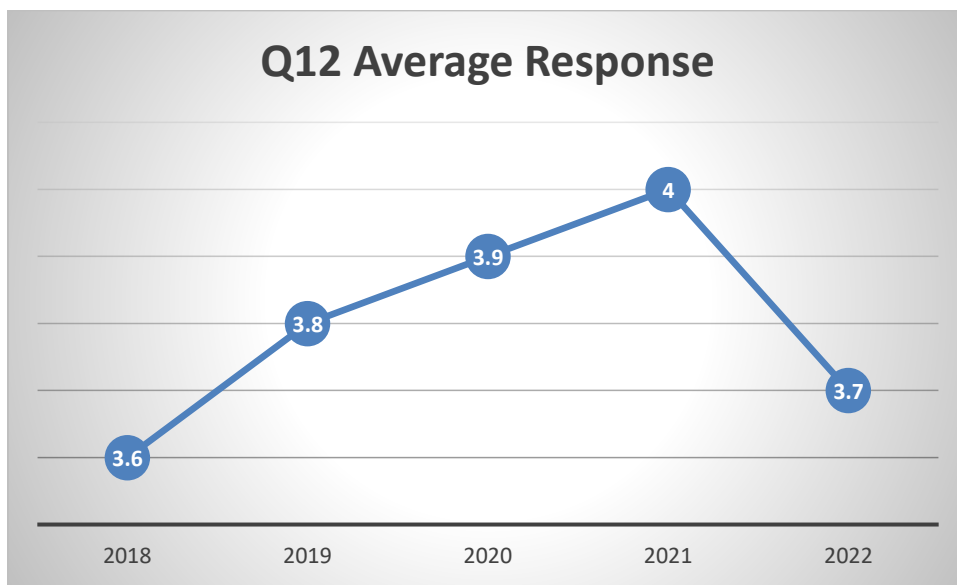


Q11	2018	2019	2020	2021	2022
Strongly Agree	34	46	39	42	29
Agree	50	56	42	48	37
Neutral	34	32	25	17	23
Disagree	7	7	3	2	5
Strongly Disagree	10	3	4	2	2
n=	135	144	113	111	96

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

Figure 12 shows that the average response (3.7) is closest to “agree,” and that responses to this item have decreased since the previous year. A total of 58 of the caregivers (60%) endorsed “agree” or “strongly agree.”

Figure 12



Q12	2017	2018	2019	2020	2021	2022
Strongly Agree	24	30	41	30	32	25
Agree	31	51	52	50	53	33
Neutral	22	35	38	24	21	28
Disagree	6	7	7	5	2	6
Strongly Disagree	4	11	5	4	1	4
n=	87	134	143	113	109	96

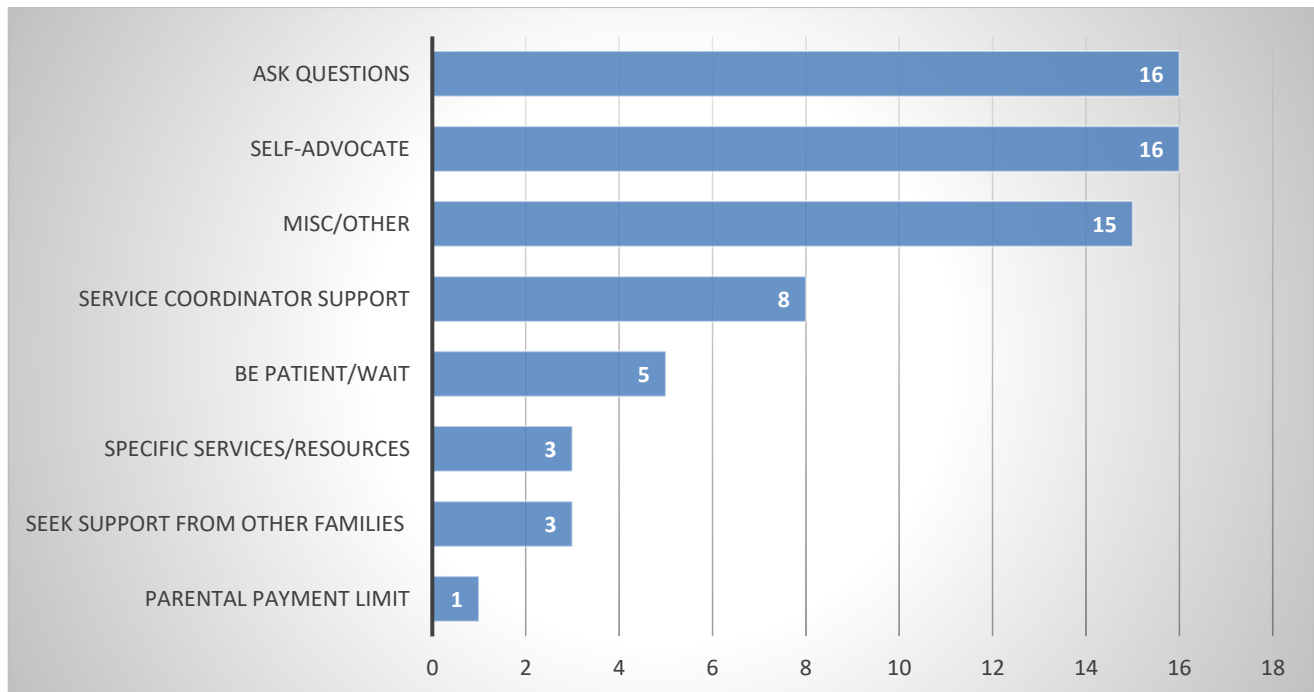
General Comment Results

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

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

Of the 101 completed surveys, 64 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 eight theme categories. The greatest advice that respondents would give to families that are new to the program is to Ask Questions (16) and Self-Advocate (16). These two themes accounted for 50% (32) of the 64 responses to this open-ended question.

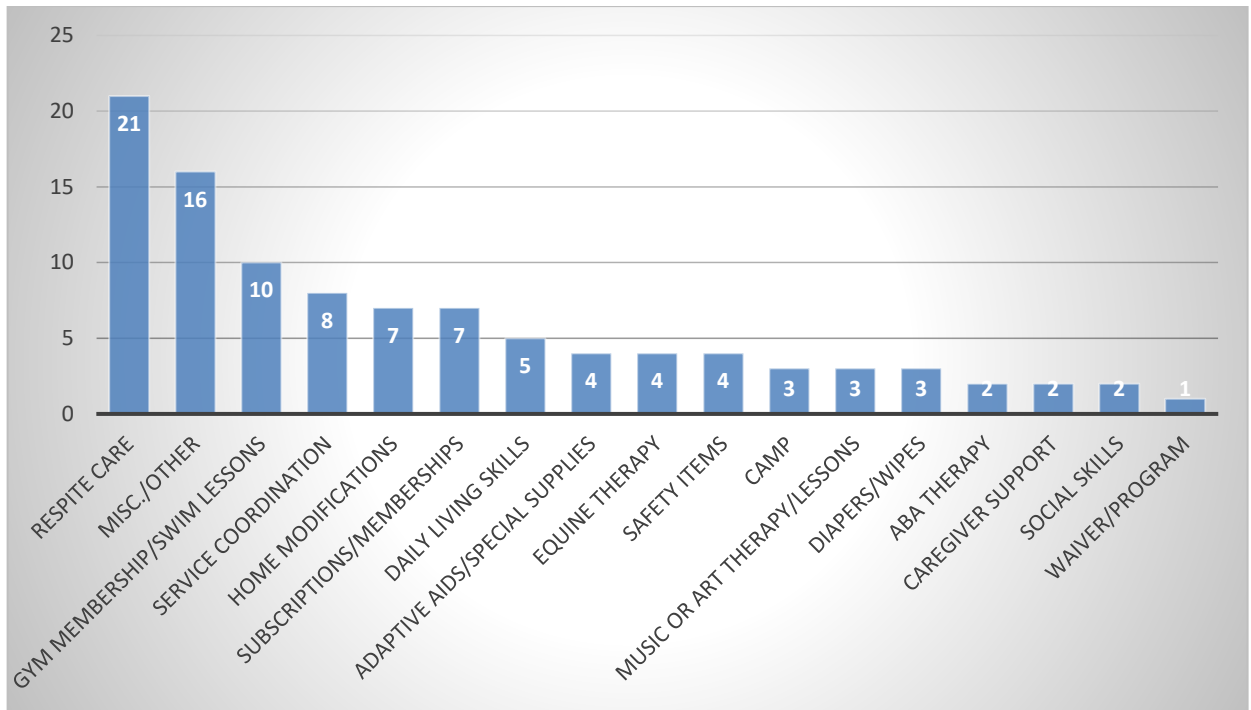
Figure 14



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

Out of 101 completed surveys, 73 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 17 theme categories. Caregivers shared that the most helpful service or support to their family was Respite Care (21) which accounted for 21% of the total responses. Positive comments were also received about the Gym Memberships/Swim Lessons (10) and Service Coordination (8).

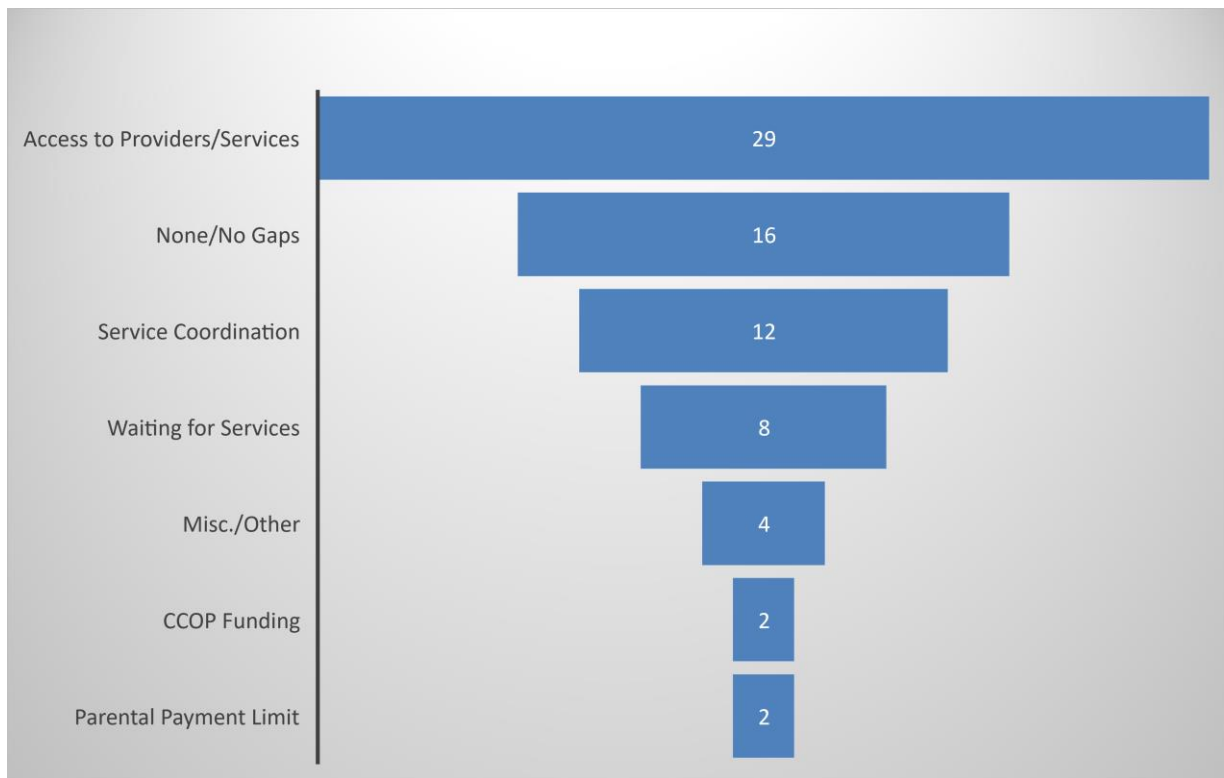
Figure 15



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

Out of 101 survey caregivers, 69 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 (29) which accounted for 40% of the total responses. An area of strength was noted in that 16 of responses (22%) indicated there are no gaps in services/support.

Figure 16



Appendix A

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

Ask Questions (16):

- Ask a lot of questions. Be honest about any struggles.
- Ask about anything and everything you may be interested in. It is not offered up.
- Ask a lot of questions.
- Ask everything, Do not keep doubts or questions.
- Ask lots of questions about services available and be patient.
- Ask questions, there is so much you can miss out on if you forget something. The team is always ready to assist you!
- Ask questions, you may find resources that you didn't know existed.
- Ask what kind of services my child will benefit and how the county will help.
- Ask-It never hurts to ask.
- Be creative when asking for services, stay connected with your social worker, ask questions and follow up.
- Be patient , ask questions, get resources for your child that will be approved to help with timing.
- Be patient and ask questions.
- Don't be afraid to ask questions.
- Don't be afraid to ask questions and request everything you can think of. If the program can't provide something your coordinator probably can find a suitable replacement.
- Keep asking questions.
- Start ASAP, Ask Questions.

Self-Advocate (16):

- Be an advocate for your child and be involved.
- Be sure to be open and honest with all forms of needs of the child (and Parents). Don't be afraid to ask for something.
- Be the squeaky wheel.
- Do not be afraid to ask if something is covered.
- Do your homework on what is out there for your child and educate yourself on what they need and what is offered in the community. Also start hunting for respite help right away. It is very difficult to come by and is all your connections school, church, community to find someone that can work for your family and child.
- Document Contacts, Follow up.
- Don't be shy, Be honest, realistic Be a bold voice for your child.
- Don't Google! You have to be your child's advocate. Sometimes even medical professionals act like a disability is a death sentence.
- As soon as you can get on Waiver program. Keep Calling!!! Bugging them to find out your status. Do not wait for them to call. You be PROACTIVE.
- Don't wait till your in crisis to ask for help.
- Educate yourself on all the programs. It's complicated but helpful.
- Elevate your concerns to the supervisor if you not getting what you want.
- Keep a constant ear/eye out for opportunities to help improve your child's life.
- Make all requests no matter what to your worker the worst thing can say is No.
- Please continue to ask and advocate for your child and family. It costs a lot of money to try to meet your child's needs and get support and therapies. Service coordinators will change frequently-which is frustrating -but continue to advocate.
- You know your child best as to what he/she needs. Don't hesitate to ask for such services, not just once, but again, because you never know funding may change.

Misc./Other (15):

- Ask about the programs that will be lost by joining this one. (Especially insurance HMO)
- Be as receptive as possible for the services you would like for your child.
- Great Program
- Highly Recommend!
- I am new to the program-I need advice.
- It is a great program.
- It seems more helpful than other programs.
- Make sure you know what you are getting into. (Responsibility) It can be more than 18 years
- Responsibility doesn't end at 18 years.
- Take the time to go through the program it's well worth it.
- The programs are really helpful, so take advantage of them.
- We are new to the program ourselves and would encourage others to apply.
- We are very satisfied with the CLTS Program.
- We haven't used yet.
- Research-plan ahead for transition time.

Service Coordinator Support (8):

- Before meeting with family coordinator have a general idea of goals you want for your child, and what services could support those goals.
- Do your research. Download the PDF: CLTS Your coordinator may not know things that are available to you because they are new to their job responsibilities.
- Help all families understand the "pots" of money available and work with them to access funds. It was disappointing to hear from other waiver parents that they got what I was asking for but was told there was no money, or that isn't covered.
- Highly recommend building a strong relationship with your service coordinator. Be proactive in seeking out activities.
- If you encounter an issue or anything contact your worker. They are fantastic at providing resources.
- Service coordinator was so helpful for our family. She even attended an IEP meeting to help advocate for my son.
- Talk to your coordinator! They have so many resources!
- The services offered are not sufficient, although service coordinators bring the best that is provided. The limited benefits. Request for new funding to support more effective programs.

Be patient/Wait (5):

- Ask lots of questions about services available and be patient.
- Be patient , ask questions, get resources for your child that will be approved to help with timing.
- Be patient and ask questions.
- Just be patient the program is working in the best of your interest.
- Prepare to wait.

Specific Services/Resources (3):

- Kids with special needs are a handful, could use help with paying for, the zoo, museums, baseball game, or pass's so I could take my daughter swimming.
- Mileage reimbursement is not a guarantee.
- We have mediators for our son. It helps a great deal. Someone who gives you a break and you can breathe. It is also great to call 211 when there is issues in your home. It calms everything down.

Seek Support/Connect w/Other Families (3):

- Network with other families to see what types of services are provided. Sometimes it's hard to know what types of things are covered.
- Reach out to other families in the community.
- Talk to other families to find out what services are available.

Parental Payment Limit (1):

-Parental Payments are messed up and it hasn't been addressed. We are told to figure it out ourselves instead of the financial department helping or even service coordinator.

Appendix B

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

Respite Care (21):

- So far all of them, but Respite care has been super helpful for many reasons.
- Respite.
- Respite, Puberty resources, YMCA memberships, wipes.
- Respite, Waiver helpful in obtaining items to help child develop.
- Respite.
- Providing respite care and items needed for my son.
- Respite care, passes to the zoo, creative solutions.
- Respite was very important and helpful. Wish there wouldn't be so much paperwork between us and providers.
- Respite, monthly childcare allotted hours, mentoring hours and membership to the Sensory Club.
- Gym membership with access to a pool for sensory exercise. Respite and Life skills. Please work on getting YMCA's set up for waiver payments, what happened??
- Respite.
- Respite.
- Respite.
- Respite.
- Respite.
- Respite.
- Fence, respite.
- DLS and Respite and what is available.
- Diapers, knowledge about home/vehicle modifications, specialized childcare to cover gap in summer services.
- Respite Care / Childcare to allow us to know our child was cared for.
- Respite, DLS, and misc. items purchased for his needs.

Misc./Other (16):

- I have received NO services.
- My child was excited about services.
- The services provided so far have been amazingly helpful for us.
- Dr. Seymour.
- My daughter therapy company, as well as her coordinator.
- Referrals to other services, specialties for my child.
- We have only received additional "homework" no assistance has been provided yet.
- Counseling psych meds. The team always working together was so helpful.
- We are new to the program.
- Transitional Services from Child to adult CSS.
- One on one therapy.
- Support for Therapy equipment.
- We haven't used yet.
- Just started the program. Can't answer now.
- Haven't really explored much of the programs.
- Respite, DLS, and misc. items purchased for his needs.

Gym Membership/Swim Lessons (10):

- YMCA membership, Zoo pass Other medical equipment (go to seat, bath seat, etc.).
- Respite, Puberty resources, YMCA memberships, wipes.
- Memberships – Outdoors.
- Gym membership with access to a pool for sensory exercise. Respite and Life skills. Please work on getting YMCA's set up for waiver payments, what happened??
- We really haven't utilized services recently. Paying for swim lessons in the past was helpful.
- Respite programs like the YMCA and Pool Pass. We don't have additional income as we are down to 1 income as I needed to stay home and care for my child. Things like this would not be possible for her to be part of without the financial help-Plus she gains so much being able to be in the community.
- Assistance & Memberships to gym, swimming lessons, support with pull ups through Medicaid.
- Swim lessons, Music Therapy, Team up camp.
- YMCA, Personal Trainer, Social Group, Swim Lessons.
- YMCA.

Service Coordinator (8):

- Someone listens to us and provides what we need. Recommendations on services were helpful.
- We have many people working with the family. It is call Wrap around us.
- My daughter therapy company, as well as her coordinator.
- The staff is very kind, available and willing to help. They listed several resources that could potentially be helpful for my child.
- The communication with the coordinator. Hardly any services provided in 2021/after.
- The explanations that our service coordinator has provided is excellent!
- Horseback riding, supplies, knowing I have a case manager to help me out when I have questions. It's a good support for me.
- The staff is kind & willing to help.

Home Modifications (7):

- Bathroom remodel and fence.
- Wipes, zoo pass, bike, fence, door alarms.
- Swing -always and the larger frame. The Autism conference-gives us a chance to a family activity and learn more about Autism and be with other Autistic families
- Fridges, Freezer, Cabinets.
- Renovation of bathroom, art therapy.
- Fence, respite.
- Diapers, knowledge about home/vehicle modifications, specialized childcare to cover gap in summer services.

Subscriptions/Memberships (7):

- Getting a zoo pass makes my child happy.
- Extra- curricular activities like Taekwondo, and membership. To alike sports club that provides multiple services, exercise, social and life skills programming throughout the year.
- Wipes, zoo pass, bike, fence, door alarms.
- Respite care, passes to the zoo, creative solutions.
- Respite, monthly childcare allotted hours, mentoring hours and membership to the Sensory Club.
- I really haven't had any so I don't know what to say. I've had custody of my daughter and the only thing I have received was a zoo pass.
- Membership to the Sensory Club and the GPS Tracker.

Daily Living Skills (5):

- The daily living skills my daughter has been learning.
- Gym membership with access to a pool for sensory exercise. Respite and Life skills. Please work on getting YMCA's set up for waiver payments, what happened??
- Daily Living Skills, but we are only getting partial hours due to unavailable staff for service companies.
- Unfortunately, one service provider can support, one cover the allocated hours. If more service providers are allowed to share. I can get more hours covered. Right now, times are unutilized.
- ABA Services, Daily Living Skills.
- Respite, DLS, and misc. items purchased for his needs.

Adaptive Aids/Special Supplies (4):

- YMCA membership, Zoo pass. Other medical equipment (go to seat, bath seat, etc.).
- Medical services not covered by insurance, empty pill capsules, oozy adhesive removal.
- Assistance & Memberships to gym, swimming lessons, support with pull ups through Medicaid.
- Diapers, knowledge about home/vehicle modifications, specialized childcare to cover gap in summer services.

Equine Therapy (4):

- Horseback riding therapy has been extremely helpful.
- Cooper fatigues so easily so we really we are able to get him into Life Striders this time around.
- Horseback riding, supplies, Knowing I have a case manager to help me out when I have questions. It's a good support for me.
- Life Striders, sibhops, camps in summer.

Safety Items (4):

- GPS is good for my family.
- So far items received to help Blake stay safe and help him get through the day.
- Membership to the Sensory Club and the GPS Tracker.
- Wipes, zoo pass, bike, fence, door alarms.

Camp (3):

- Help with ABA and other social skills activities. Bike camp was incredible.
- Swim lessons, Music Therapy, Team up camp.
- Life Striders, sibhops, camps in summer.

Music & Art Therapy/Lessons (3):

- My Signing Time, Music Therapy.
- Renovation of bathroom , Art therapy.
- Swim lessons, Music Therapy, Team up camp.

Diapers/Wipes (3):

- Wipes and the crash pad. Also finding respite options, even though we haven't had to use them yet.
- Respite, Puberty resources, YMCA memberships, wipes.
- Wipes, zoo pass, bike, fence, door alarms.

Applied Behavior Analysis (ABA) Therapy (2):

- Help with ABA and other social skills activities. Bike camp was incredible.
- ABA Services, Daily Living Skills.

Caregiver Support (2):

- Swing -always and the larger frame. The Autism conference-gives us a chance to a family activity and learn more about Autism and be with other Autistic families.
- Respite care, passes to the zoo, creative solutions.

Social Skills (2):

- Help with ABA and other social skills activities. Bike camp was incredible.
- YMCA, Personal Trainer, Social Group, Swim Lessons.

Waiver/Program (1):

- Respite, Waiver helpful in obtaining items to help child develop.

Appendix C

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

Access to Providers/Services (29):

- Limited resources.
- Speech therapy at school is insufficient and we have to pay out of pocket for this critical service which not covered by CLTS.
- Services covered by CLTS, CCS, CCOP do not have 1 stop shop, info sheet on which brands providers what services it is hard to understand if services are provided by more than one agency.
- It's difficult to know what to ask for when you don't know what is available.
- The gap is in suggesting the service that is actually starting. There is quite a lot of paperwork and seems a little slow to start, okay if not a crisis situation . This is understandable though, due to the high volume of needs and lack of facilities and providers.
- We have not had a respite provider in almost a year. At the beginning of each year there is a delay in services due to the contracts.
- Getting projects approved.
- Took too long to get services. Hard to find respite providers through companies. Still haven't received any. Had to find our own.
- Large gross motor activities-a basketball hoop would provide my kids to play together and be safe and get exercise- it is disappointing we have a save for a hoop for him to play with his siblings. Fitnow-Never contacted me YMCA never returned any of my phone calls.
- Respite providers!
- We barely get out because it is hard to find activities my son likes and can get involved in. The one thing we like to do as a family is go to the YMCA to swim. My child loves that but unfortunately they took that away from us. Right now, they don't know when it will get approved. I have been waiting for a while now.
- School related items, items that are considered (typical parent responsibility) Need to be more open cause not all disabilities are the same, my son requires different needs due to one his disabilities.
- Not all supports are covered by the program-like adaptive bikes and fencing for yard.
- Not enough activities of daily living hubs, facilities, care providers.
- Not enough staff from service providers. Unable to cover 6 hours per week that will allocate more service provider shall be allowed to share.
- There were gaps in service for my son because it is hard to find caregivers for a severely disabled child under 25/hr.
- Application, Programs for Safety in the community, i.e., Swim lessons.
- So far not any-Just waiting to hear how much respite care pays so I can hire someone.
- Unexpected changes in services.
- The services for kids with mental health concerns are minimal! The waiting list is too LONG!!
- Summer Care for kids with special needs. Regular Daycares cannot accommodate needs like pull up changes, assisting with clothing changes. Very difficult to find group summer care.
- Just sometimes hard to get out of workers what is and not covered-seems like it is different for different areas/families, etc.
- Hard to understand what is covered by which department or service organization.
- We have 4 children and youngest is Autistic. It's hard at times to do things as a family. It would be helpful if there was a list of caregivers to provide babysitting or respite if we need to go somewhere. We do not have family that are able to serve in this capacity.
- Summer.
- Some services we did not get, and we are disappointed.
- We are new to transition-gaps between all providers, school, CLTS, DVR- all have different goals - hard to navigate different routes and people. Thank you for all of the assistance. Jenna is wonderful!
- Communication re: funding and it's availability. We didn't know it was out by the time we were ready to use. (midyear).
- Not enough at this time.

No Gaps (16):

- No.
- No.
- None.
- None, experienced.
- None at this time.
- No.
- No.
- No.
- N/A.
- No gaps.
- We are just beginning the process-so we do not see any gaps currently.
- No.
- No.
- N/A.
- No.
- No.

Service Coordination (12):

- Our coordinator is new and lacks the experience needed to be helpful to our family.
- My service coordinator is amazing!
- Coordinator was not getting back to us. Very bad experience!
- Communication - Delays- Each case manager has too many families.
- I have had 4 case workers in the span of 2 years. Prior, I had 1 long-term case worker who knew me and my kids, worked hard to answer my questions and get supports in place. The new person I just met seems like she is on the ball, and I am hopeful. I didn't feel heard for 2 years. Instead of working with me and really listening, my children's plans were filled with things the case worker thought were best (or maybe just the things she was aware of or could set up quickly) At my last visit, my new case worker cleaned up my plan and is working hard to get us the support we requested.
- Turnover is very high around service coordinators. Communication is SLOW.
- The constant changing of service coordinators is beyond frustrating. Every time a new service coordinator comes aboard, it is starting all over. There is no continuity.
- Unable to answer any of the questions, as we are still awaiting services.
- New/Untrained Staff.
- Our child's information was available to another county and that information was leaked. Our coordinator was in no way helpful in helping us figure out why another county had our child's information. Our child is under 18 and there's a great concern about health/medical information used by someone other than our child. Your financial department is a mess and has been since you switched from a set payment to a sliding scale.
- New hires do not know what is available for families.
- We are new to transition-gaps between all providers, school, CLTS, DVR- all have different goals - hard to navigate different routes and people. Thank you for all of the assistance. My service coordinator is wonderful!

Waiting for Services (8):

- Yes, super long wait for services. No clear direction after a birth diagnosis. A lot of negativity.
- It took 6 months before I received a response for services, but it was well worth it in the end.
- The delay in response, constant gaslighted needs and generally exhausting experience of waiting and waiting for EVERY little thing has become so awful with Waukesha since the pandemic, This was completely different, even early in the pandemic. Overall, the waiver is only helpful with respite and large/high-cost things at this point because the amount of waiting and playing games with county workers to anything else makes it not worth asking. Waukesha was not like this before!
- Unable to answer any of the questions, as we are still awaiting services.
- We are brand new to the program, but the wait time is extremely long.
- yes, due to wait list.
- The waiting list.
- A very long wait list to get into the program. Our son was diagnosed Jan 2022 and we started receiving services Oct 2022. During the wait time we paid for a fence and door sensors out of pocket. Very happy with the services we have been receiving now that he is in the program.

Misc./Other (4):

- Too many to write ???
- We haven't used yet.
- Not following, my recommendation was not met.
- I need more handholding for now until I fully understand the process.

Children's Community Options Program (CCOP) funding (2):

- CCOP funding runs out too quickly-The activities are what we benefit from and use the most. Swimming, camps, YMCA. These are programs where she gets to be with other children learn skills and have fun. There are very limited options for us, so this is so important and like so many families often on 1 income homes, cost is also an issue if not funded by CCOP. The younger children, less than 4 or just 4 have such limited opportunities to be in the community and what is offered through school interests is very limited. We have taken advantage of the great programs through Children's Variety, but I would love to see more options for us. Many parents are still learning how to care their child at this point and it's very isolating. It would be great if we had some programs available to home and safety and appropriate special interactions-like an early childhood meet up group for family's/children on the waiver, or outings we could do to meet other families and children. Also, we love our Service Coordinator, she does a great job and is always helping find the best resources for Molly. I just wanted to pass that along!
- Communication re: funding and it's availability. We didn't know it was out by the time we were ready to use. (midyear).

Parental Payment Limit (2):

- Our child's information was available to another county and that information was leaked. Our coordinator was in no way helpful in helping us figure out why another county had our child's information. Our child is under 18 and there's a great concern about his health/medical information used by someone other than our child. Your financial department is a mess and has been since you switched from a set payment to a sliding scale.
- No transparency in billing/Financials-HUGE GAP.