

2021

Children with Special Needs

Consumer Quality Assurance Survey Report



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Executive Summary

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

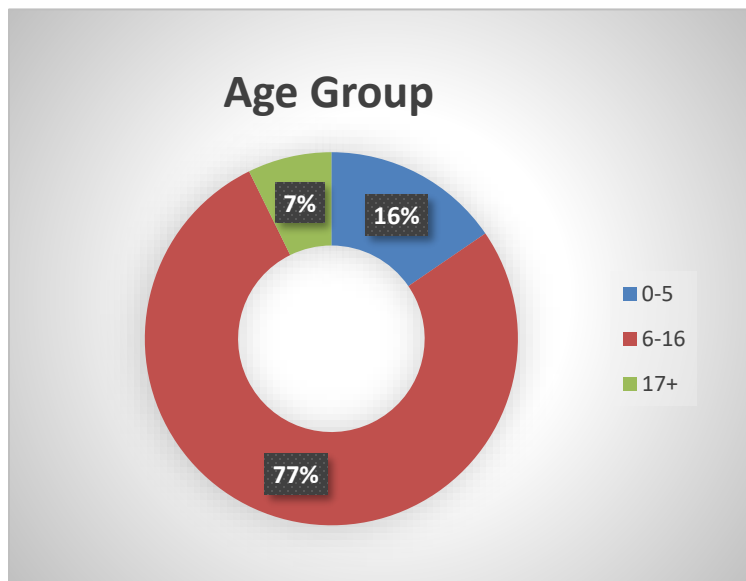
The CSN Consumer Quality Assurance Survey is part of an ongoing commitment to continuous improvement and quality service. The survey consists of a questionnaire that was developed as a means of gathering feedback from the families we serve. This Department of Health and Human Services evaluates and analyzes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

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, 2021.”*

A total of 110 caregivers responded to the age group question, with the findings shown in **Figure A**. Most caregivers (85) reported their child was in the 6-16 age group, 17 indicated their child was aged 0-5, and 8 said their child was 17+.

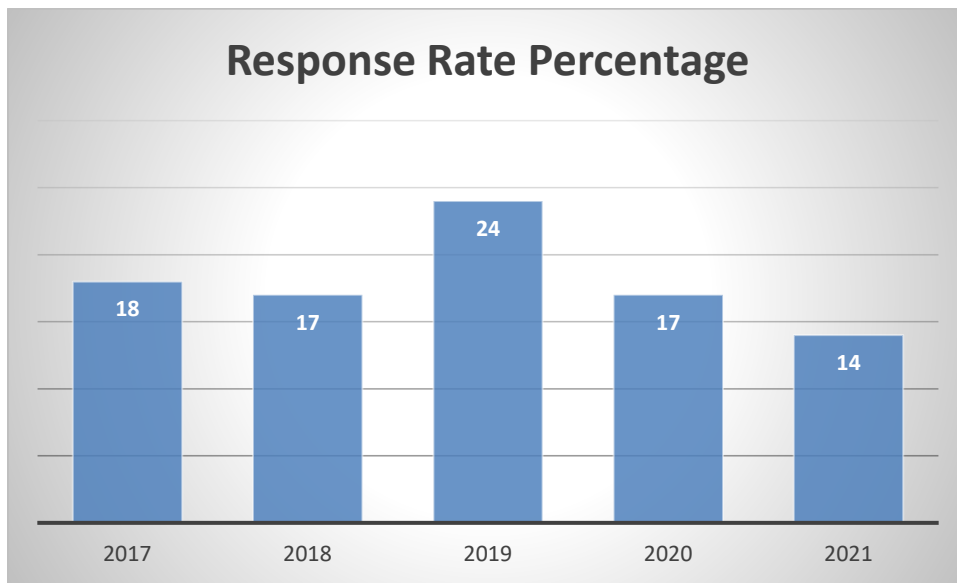
Figure A



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 2021, 793 paper surveys were sent to valid parent/guardian addresses, and 112 completed surveys were returned. **Figure B** captures the response rate from 2017-2021. 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.

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 high 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 98% of caregivers endorsing “strongly agree” or “agree.” (Q1)
- Average levels of satisfaction with service coordination have increased 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).
- Most caregivers (75%) 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, 2020. (Q8) However, survey responses indicate that families ultimately feel less prepared for the transition, with results being at their lowest in five years. (Q9)
- The percentage of caregivers indicating that their child experienced severe health and/or safety concerns while waiting for services is increased for the first time in five years. (Q10) However, most families (83%) felt that they were able to address their child’s need 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) increased, with less than 4% of caregivers endorsing responses in the lowest two ranges.

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.

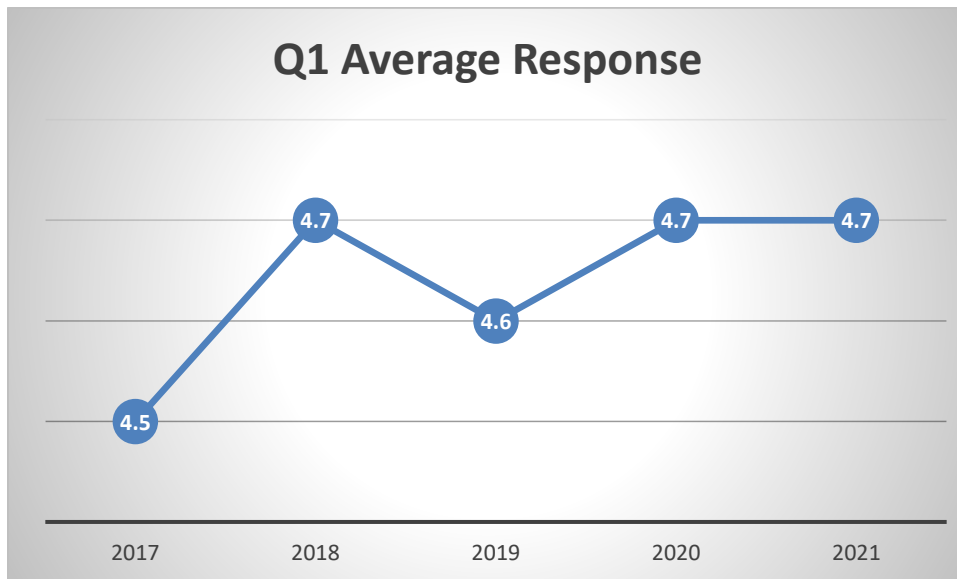
- Question 9 on Page 14, states, “My child was 17 years old as of July 1st, 2020; I feel that as a family we are prepared for the transition to adult services”. This year’s average response dropped seven-tenths of a point to our lowest overall survey response of 3 – Neutral. To address this drop in score, the CSN leadership team joined in partnership with our Aging and Disability Resource Center (ADRC) to collaborate in providing additional education opportunities for families to better understand the process and resources available to them during this time of transition. Our first collaboration was to create a quarterly virtual training which discusses the transition process. This opportunity was promoted in CSN newsletters, on the ADRC County webpage, and by service coordinators to families. The second collaboration was that all youth who were ages 16 and older in January of the calendar year had a copy of the ADRC’s Transition Guide (<https://www.waukeshacounty.gov/globalassets/health--human-services/adrc/transition-guide-2022---march-update.pdf>) mailed to their home for parents to review and begin exploring adult service opportunities for their child. This mailing included youth who were currently enrolled in the CLTS Waiver program as well as youth on the CLTS Waiver 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 that this is the third time in five years that the average response was 4.7.

Figure 1

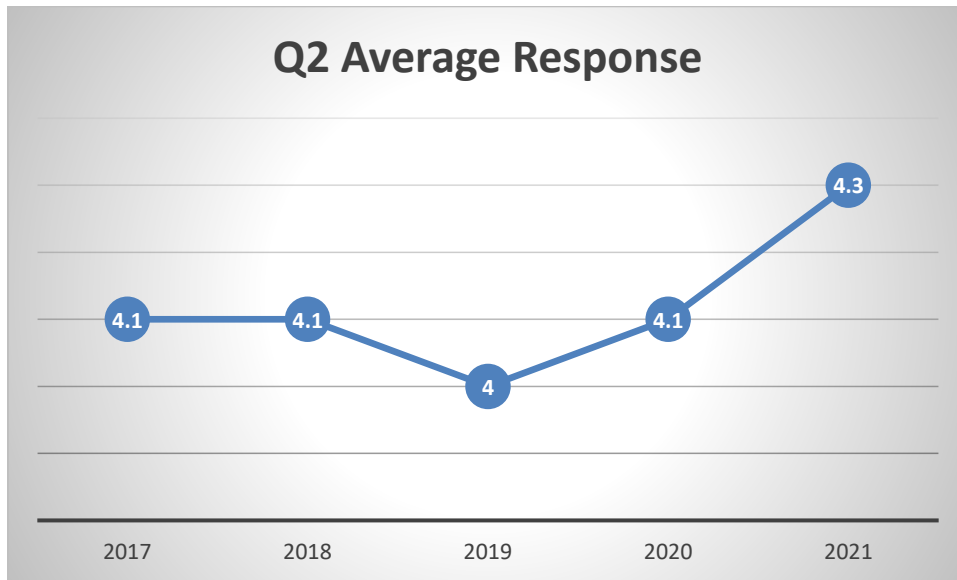


Q1	2017	2018	2019	2020	2021
Strongly Agree	57	104	106	86	85
Agree	26	34	31	23	24
Neutral	3	4	5	3	1
Disagree	0	1	1	0	1
Strongly Disagree	2	1	3	1	0
n=	88	144	146	113	111

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 (4.3) is closest to “agree”, and that is the highest average response rate in the last five years. A total of 94 caregivers (84%) selected “agree” or “strongly agree” in 2021.

Figure 2

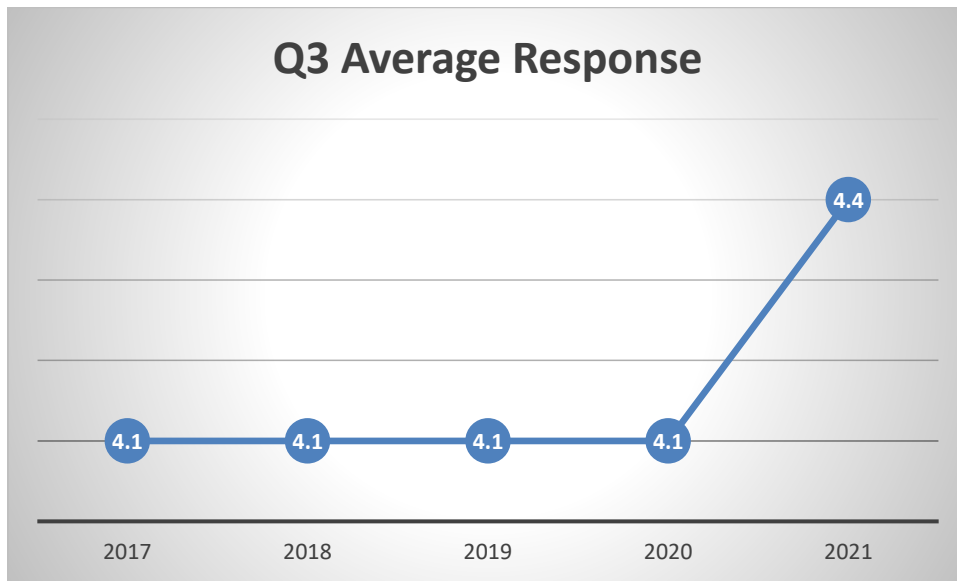


Q2	2017	2018	2019	2020	2021
Strongly Agree	36	59	63	50	60
Agree	37	52	49	39	34
Neutral	9	22	17	18	9
Disagree	3	6	11	4	7
Strongly Disagree	4	4	6	3	2
n=	89	143	146	114	112

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 that the average level of agreement has increased significantly compared to the last four years.

Figure 3

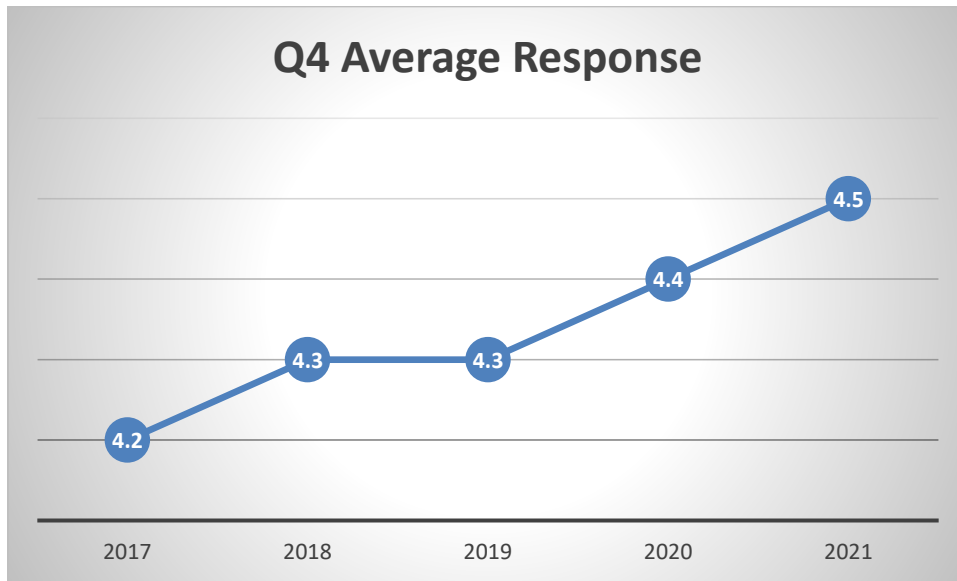


Q3	2017	2018	2019	2020	2021
Strongly Agree	37	66	68	48	68
Agree	34	43	47	47	29
Neutral	11	18	15	7	10
Disagree	4	12	5	7	4
Strongly Disagree	3	4	10	4	1
n=	89	143	145	113	112

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

Figure 4 shows that the average response (4.5) is between “agree” and “strongly agree.” The average level of agreement with this statement has gradually increased over the past five years.

Figure 4

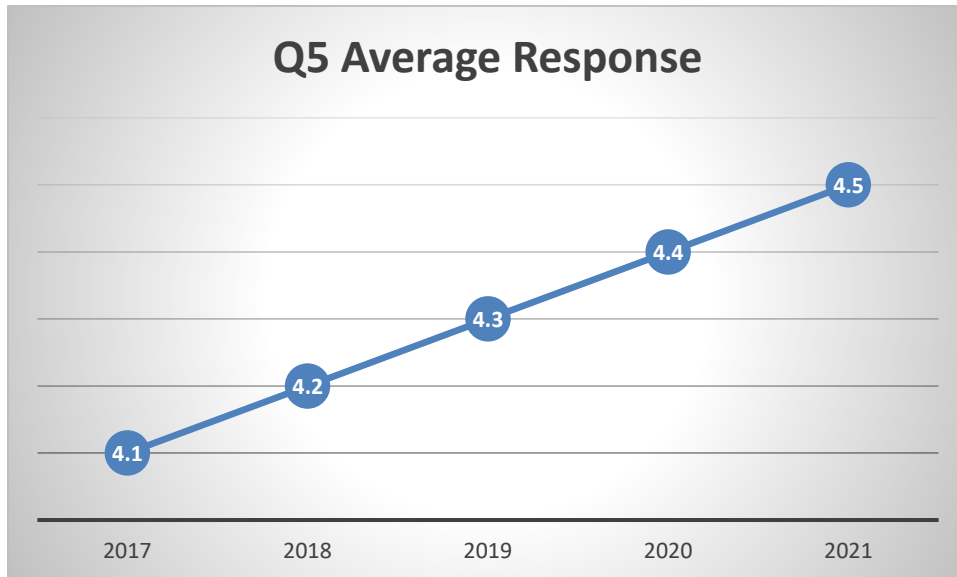


Q4	2017	2018	2019	2020	2021
Strongly Agree	40	76	82	65	71
Agree	34	42	35	35	30
Neutral	9	14	15	5	5
Disagree	3	6	9	5	2
Strongly Disagree	3	4	4	3	3
n=	89	142	145	113	111

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

Figure 5 indicate shows that the average response (4.5) is between “agree” and “strongly agree.” Response to this statement has increased four years in a row. A total of 104 caregivers (94%) selected “agree” or “strongly agree” in 2021.

Figure 5

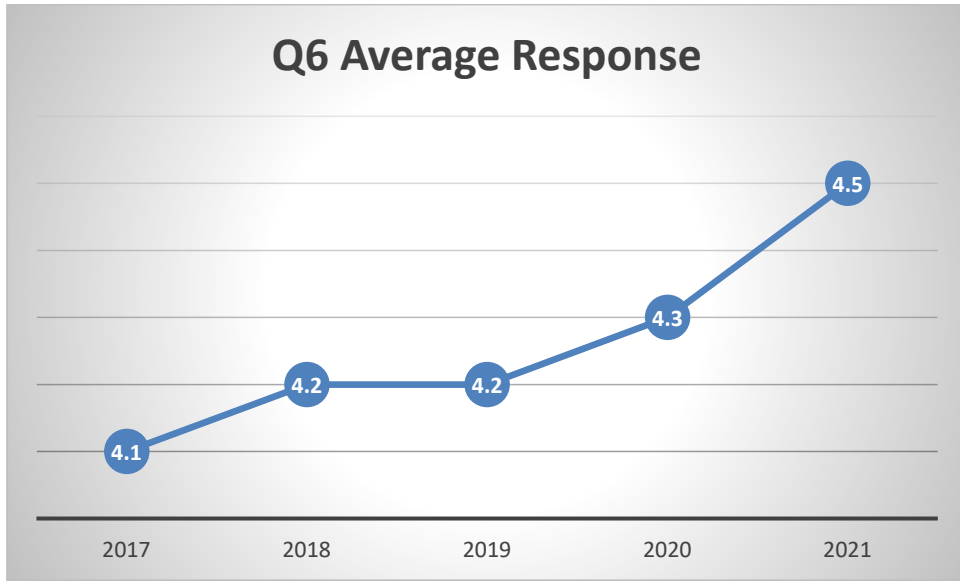


Q5	2017	2018	2019	2020	2021
Strongly Agree	36	74	78	67	68
Agree	38	43	40	30	36
Neutral	8	14	17	11	5
Disagree	5	10	6	3	0
Strongly Disagree	2	2	4	3	2
n=	89	143	145	114	111

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

Figure 6 shows the average response (4.5) is between “agree” and “strongly agree.” The average level of agreement has increased steadily over the last five years, with 4.5 in 2021 being the highest average response.

Figure 6

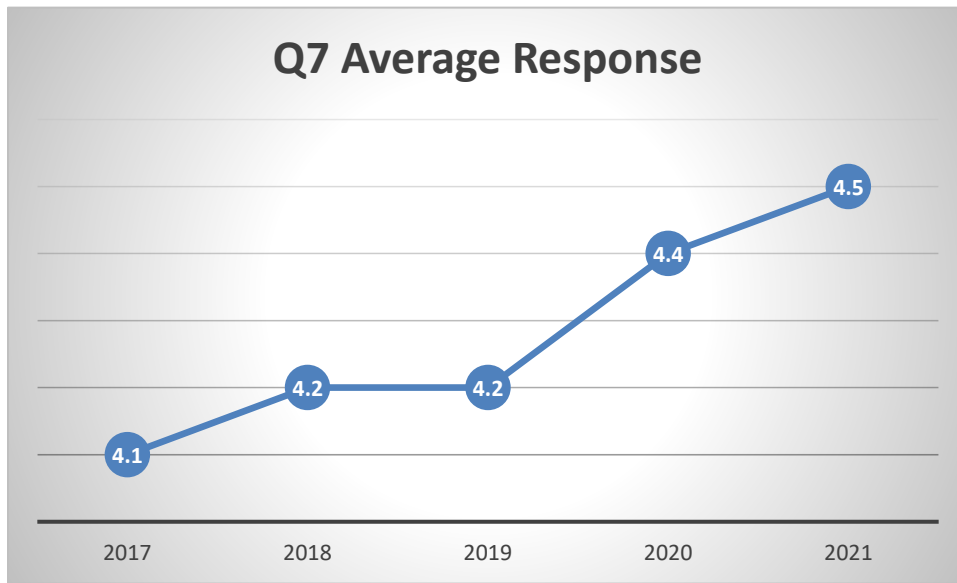


Q6	2017	2018	2019	2020	2021
Strongly Agree	40	78	72	63	68
Agree	32	35	45	36	36
Neutral	10	17	21	7	5
Disagree	3	8	4	1	0
Strongly Disagree	4	4	5	5	2
n=	89	142	147	112	111

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 (4.5) is between “agree” and “strongly agree.” The average level of agreement with this statement has gradually increased over the last five years.

Figure 7

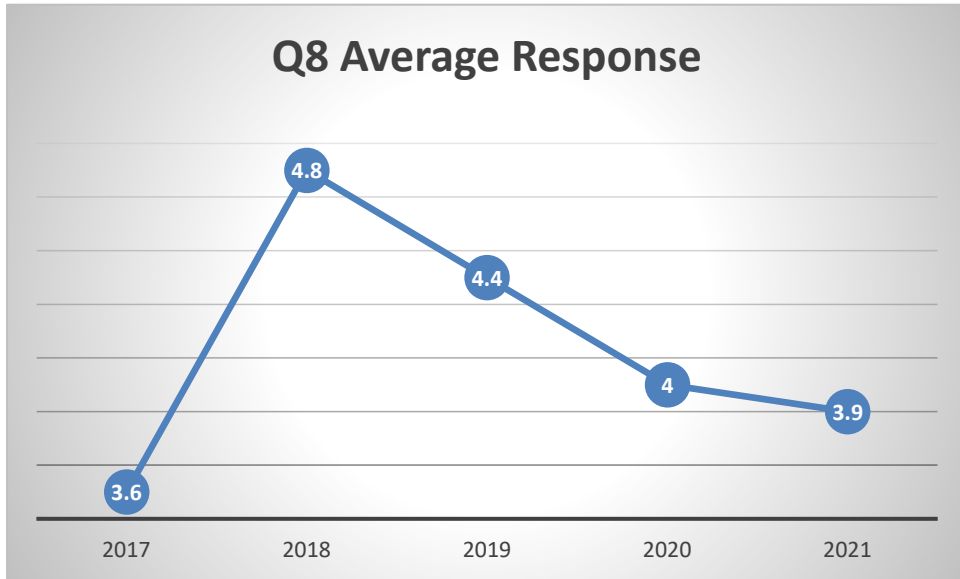


Q7	2017	2018	2019	2020	2021
Strongly Agree	36	77	74	67	71
Agree	39	35	48	37	30
Neutral	6	21	14	6	7
Disagree	1	5	5	1	2
Strongly Disagree	5	4	6	3	2
n=	87	142	147	114	112

Question 8:*[My child was 17 years old as of July 1st, 2020] My service coordinator has provided me assistance with the transition to adult services process.*

Figure 8 shows that the average response to this item (3.9) is closest to “agree”, and that this represents a slight decrease in sentiment that has persisted for three years. Note that total number of caregiver responses to this question was 12.

Figure 8

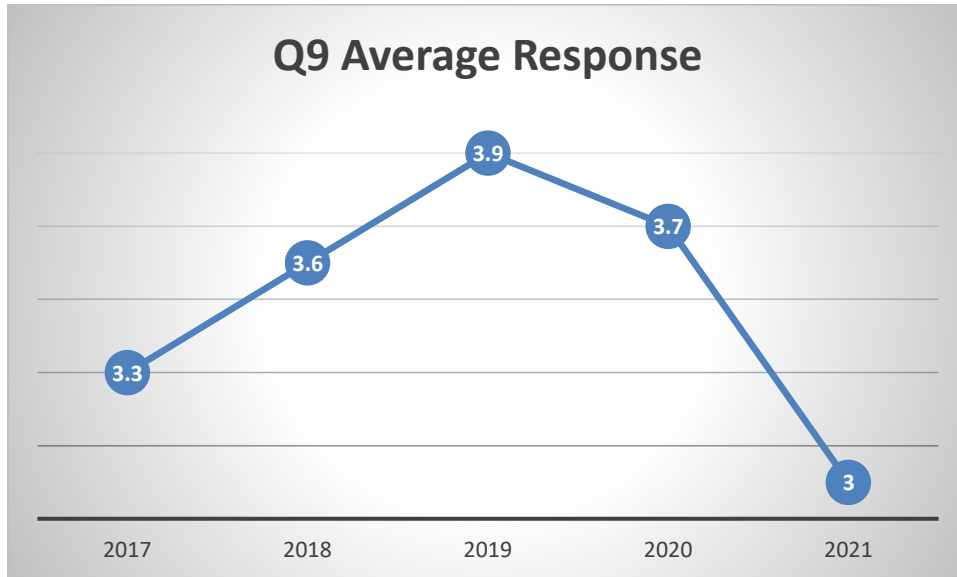


Q8	2017	2018	2019	2020	2021
Strongly Agree	9	8	4	2	6
Agree	7	2	2	1	3
Neutral	15	0	1	0	1
Disagree	2	0	0	1	0
Strongly Disagree	1	0	0	0	2
n=	34	10	7	4	12

Question 9: “[My child was 17 years old as of July 1st, 2020] I feel that as a family we are prepared for the transition to adult services.”

Figure 9 shows that the average response (3.0) is “neutral”, and that the average response has decreased significantly since 2019. Note that total number of caregiver responses to this question was 7.

Figure 9

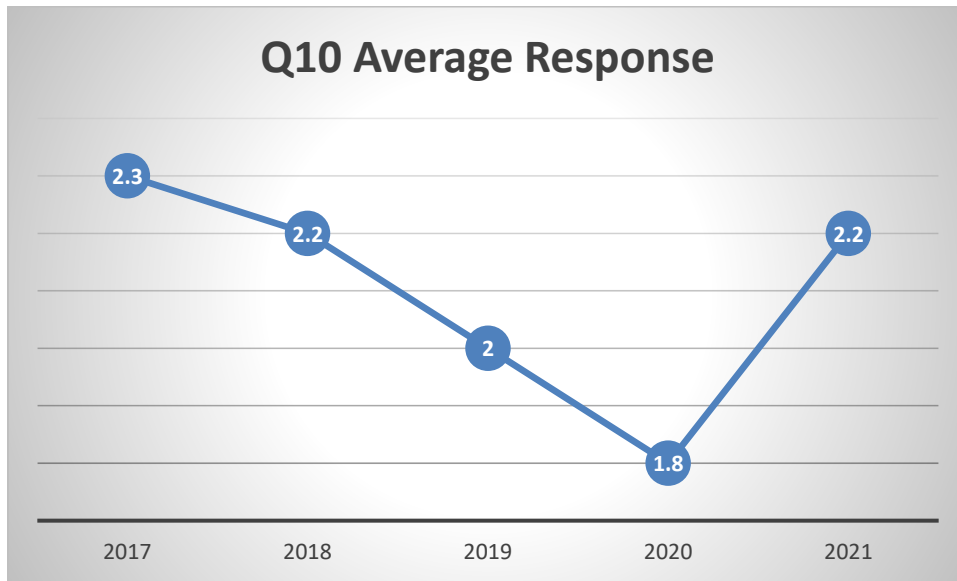


Q9	2017	2018	2019	2020	2021
Strongly Agree	6	2	3	3	1
Agree	5	4	4	2	3
Neutral	18	2	2	2	0
Disagree	3	2	1	2	1
Strongly Disagree	2	0	0	0	2
n=	34	10	10	9	7

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 to question ten (2.2) is closest to “disagree”, and that the level of agreement with this statement increased for the first time since 2017. Of the 99 responses, 77 (78%) 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

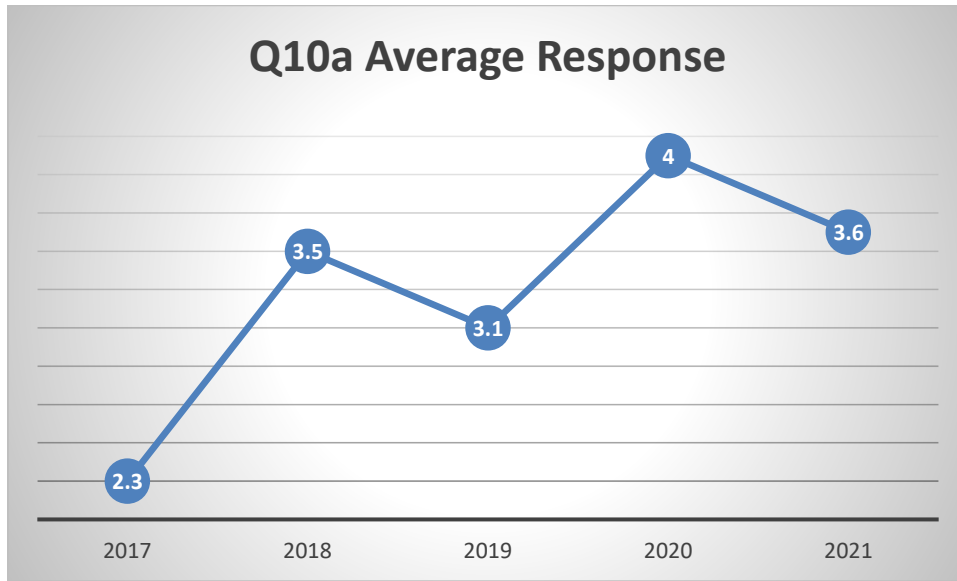


Q10	2017	2018	2019	2020	2021
Strongly Agree	8	11	10	10	10
Agree	4	10	11	2	12
Neutral	18	19	19	12	12
Disagree	13	32	29	22	19
Strongly Disagree	31	52	67	64	46
n=	74	124	136	110	99

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 that within the subset of caregivers reporting concerns (score of 4 or 5 on question ten), a lower proportion of caregivers indicated they were unable to address these concerns. The average response to the question (3.6) is closest to “agree.” Note that total number of responses to this question was 18.

Figure 10a

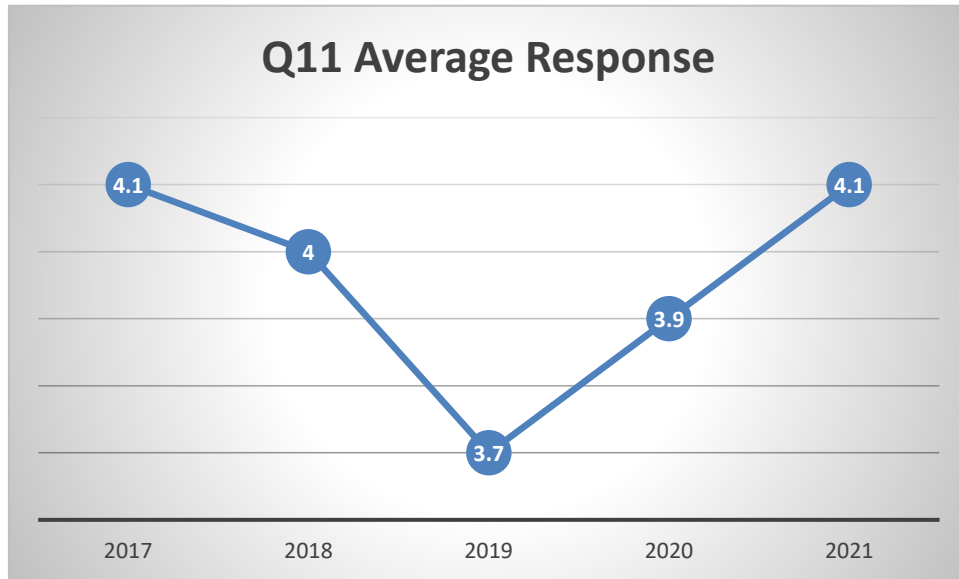


Q10a	2017	2018	2019	2020	2021
Strongly Agree	1	4	3	6	5
Agree	1	7	4	2	6
Neutral	3	6	3	2	4
Disagree	3	3	4	2	1
Strongly Disagree	4	1	2	0	2
n=	12	21	16	12	18

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 sentiment regarding this item has now increased incrementally for two years in a row. A total of 90 of the caregivers (81%) endorsed “agree” or “strongly agree.”

Figure 11

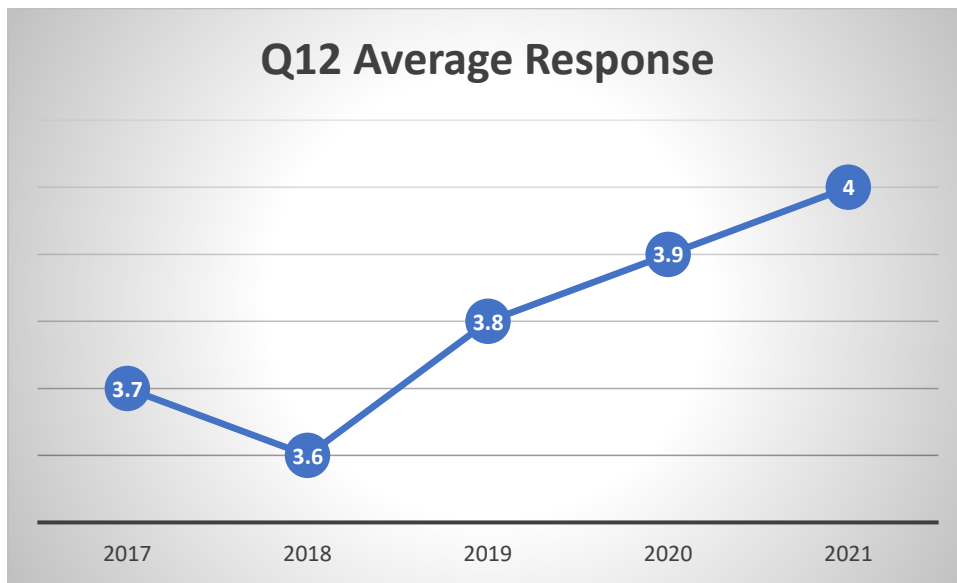


Q11	2017	2018	2019	2020	2021
Strongly Agree	34	34	46	39	42
Agree	29	50	56	42	48
Neutral	21	34	32	25	17
Disagree	1	7	7	3	2
Strongly Disagree	3	10	3	4	2
n=	88	135	144	113	111

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 (4.0) is “agree,” and that responses to this item have become more positive for the third year in a row.

Figure 12



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

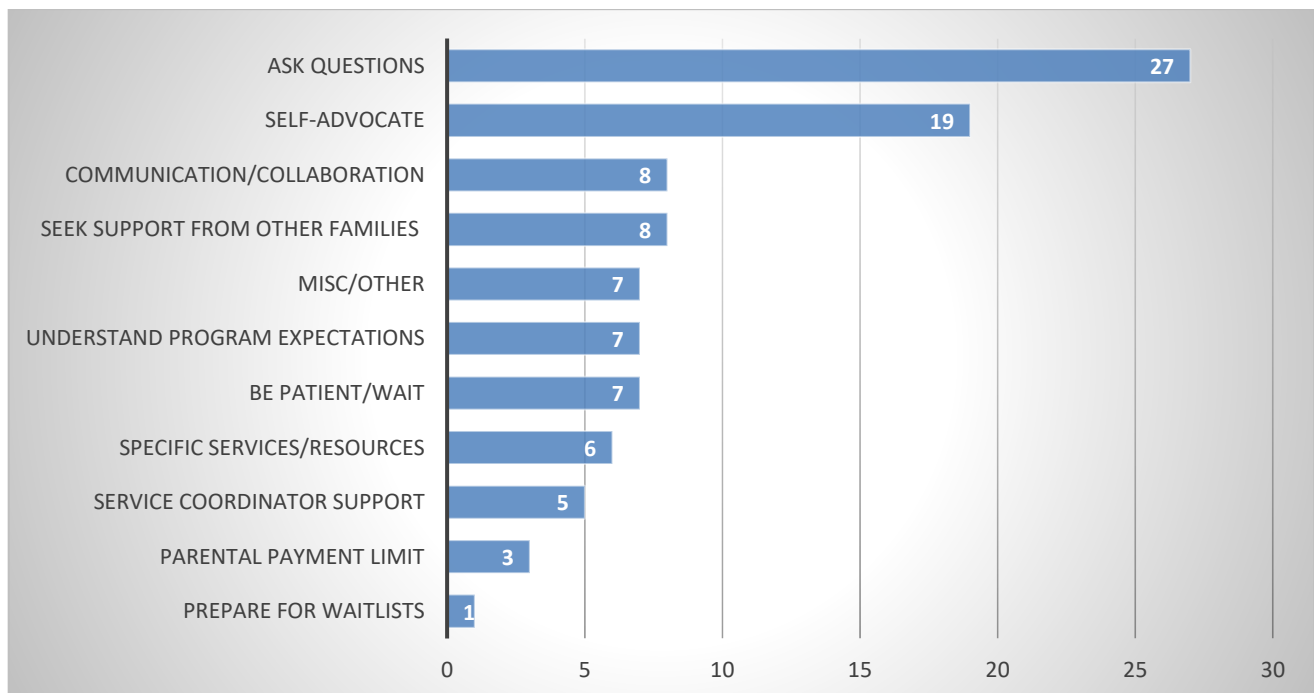
General Comment Results

In addition to rating Service Coordination statements, caregivers were also asked a three of 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 112 completed surveys, 75 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 eleven theme categories. The greatest advice that respondents would give to families that are new to the program is to Ask Questions (27) and Self-Advocate (19). These two themes accounted for 47% (46) of the 98 responses to this open-ended question.

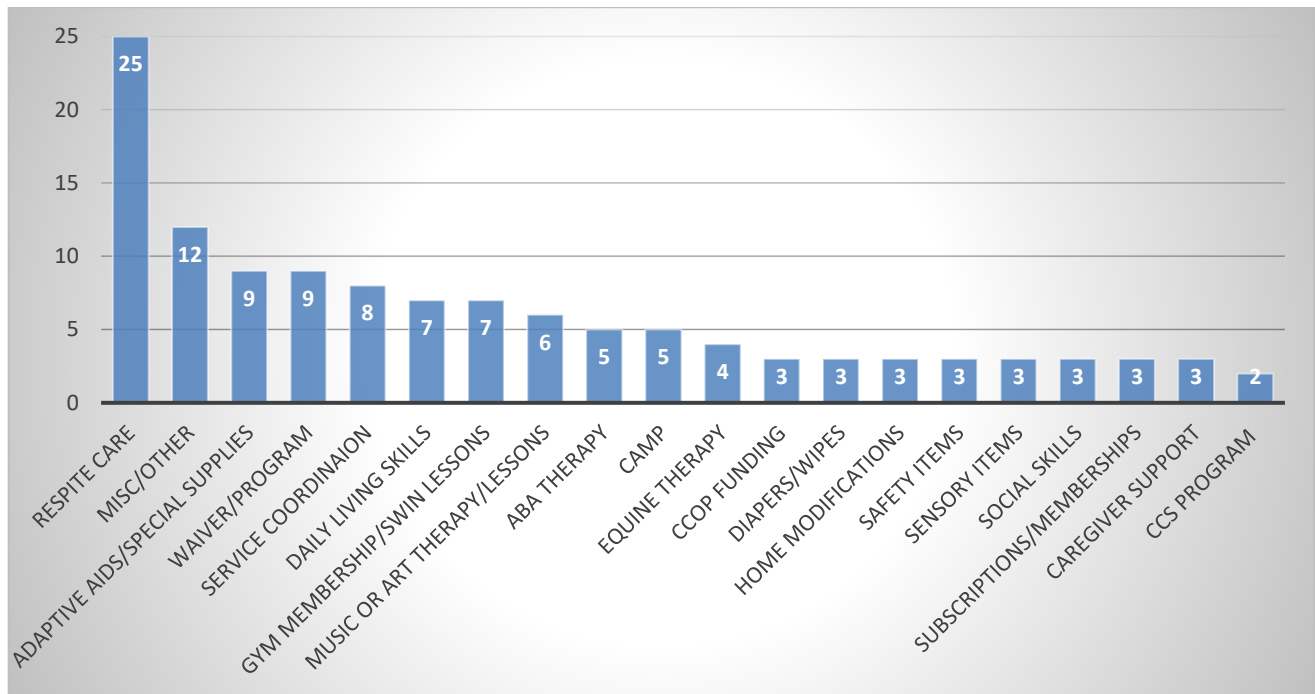
Figure 14



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

Out of 112 completed surveys, 85 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 twenty theme categories. Caregivers shared that the most helpful service or support to their family was Respite Care (25) which accounted for 20% of the 123 responses. Positive comments were also received about the Waiver Program overall (9) and access to Adaptive Aides/Special Supplies.

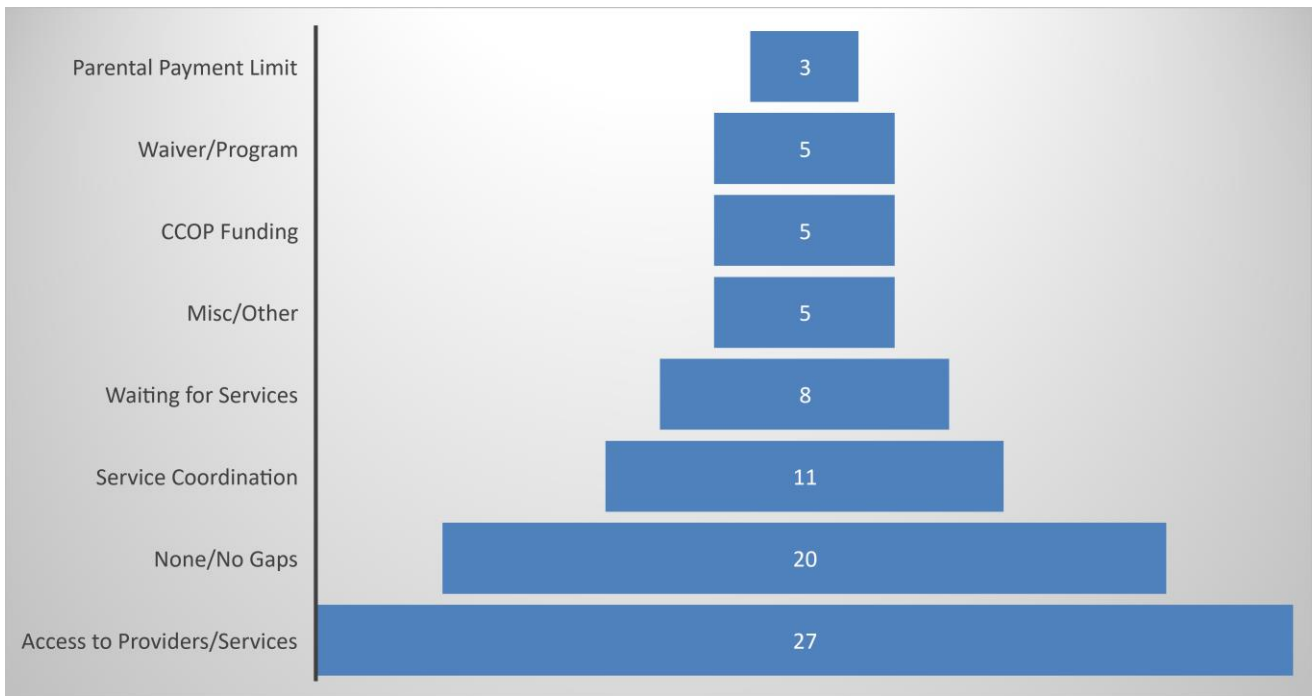
Figure 15



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

Out of 112 survey caregivers, 67 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 eight theme categories. The most prevalent gap identified by caregivers was Access to Providers/Services (27) which accounted for 32% of the responses. An area of strength was noted in that 20 of responses (24%) indicated that 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 (27):

- Ask. Ask. Ask. All of the questions.
- Ask lots of questions.
- Ask questions, no matter how dumb they might sound to you.
- Ask for everything that would help you or your child.
- Ask for services and funding sources to support those services even if you don't know if they are covered.
- Ask a lot of questions.
- Ask about disability specific activities that are family friendly.
- Ask questions, take the time to try to understand as much as you can.
- Ask about everything before you purchase on your own.
- Do not be afraid to ask if any type of service is available.
- Ask for anything that your child may need, they may be covered.
- Ask as many questions as you need to!
- Ask lots of questions as to what services can be provided. In so many instances you do not even realize that support can be provided in areas that you need.
- Ask any question that comes to mind.
- Ask lots of questions and try to get as much help as you can by the services they offer.
- Ask lots of questions.
- Continue to ask questions, these services are very useful but difficult to navigate through for a new family.
- Ask for help.
- Ask questions and seek help from your child's Doctors/Therapists to figure out what may help your child best.
- Ask questions. Research. Be open and receptive to new ideas.
- You will not know if it can happen unless you ask!
- Ask lots of questions. There are so many services available that you may not be aware of.
- Ask. Ask. Ask. About services, equipment, conferences, safety devices, etc. You do not know if something is covered if you do not ask.
- Ask for any and all services /items you might need. The worst thing they can say is no.
- Don't be afraid to ask about any support you are interested in if it is a "no" your coordinator may have other ideas.
- Ask the coordinator to really walk you through everything available to you right away.
- Ask lots of questions and request things you need even if you do not think they will be covered.

Self-Advocate (19):

- Always advocate for your child's needs.
- Reach out and ask for help.
- Be your own advocate and take part of services available. Do not waste your coordinators time.
- Do your research. Be proactive.
- Talk to the service coordinator and stay in touch to learn about more available services.
- Think ahead and apply for programs early.
- Learn how to truly advocate for the child.
- You the family do all the work. You are required to research programs, suggest them and do all the follow up.
- Engage the program for support. No question is an irrelevant question.
- Explain in detail, the scope of your needs.
- You need to do your own work (as parents of special needs kids do). The coordinators do not provide resources they just say yes or no.
- Make sure you are aware of all the help and resources the program has to offer. I was shocked!
- Continue to advocate for your child. We are their best advocate.
- Learn as much as you can because no one will fight for resources for your child as you will.
- Be open and honest with your needs. Do not feel bad about asking for help.

- Decide what your child needs most to be successful day to day.
- Be honest about your needs/struggles, there may be a solution you have not thought of or didn't realize was available.
- Be creative in your thinking. Be open to suggestions.
- Begin looking for and building a support system now so you will have people to "PLRZYLAY" for respite and DLS. Think through what ways you can use assistance in your home and out in the community!

Communication/Collaboration (8):

- Good communication and Collaboration.
- Talk to your service provider. They are full of ideas and information.
- Keep a working team.
- Keep good communication with your service coordinator. Be honest and do not take the services for granted. Be thankful that families are offered these services.
- My only advice would be, just ask/talk to your coordinator. Sometimes we as parents are not sure about what services/products are available. Talking to the coordinator will help them understand its usefulness, wait time, cost involved etc. It is okay to not know what to do, so just ask/talk to your coordinator.
- Communicate with coordinator and be creative when choosing services. Make sure you have enough information regarding available services. Follow through.
- Always inquire about resources you know of that would be helpful to your child/family and share specifics for how you feel whatever item needed is necessary. Keep Asking!
- Keep communicating with your service provider.

Seek Support/Connect w/Other Families (8):

- Ask for other families to talk and ask questions to.
- Ask other parents what programs and services they are using the program for.
- Go online and join Facebook support groups.
- Look for families with the same situations to connect with.
- Join a support group like the Autism society, so you can do outings with other parents who have kids just like yours!
- Look into community programs to create a network and community
- Talk to other families to learn how to meet your child's needs and what could be covered.
- Talk to other parents who have been through it.

Misc./Other (7):

- It would be nice to have a mentor to help families through the program.
- Exhaust all options before giving up.
- Keep faith, they are all very good.
- Once we were in the program, they try to meet all of your needs, "BUT" you will be responsible for providing your own respite providers.
- Accept the help. Be open to services.
- Set small goals and celebrate those victories.
- An overall brochure with some examples of what other families have done.

Understand Program Expectations (7):

- The program is not able to give families a list of service that they help provide, that is very frustrating. Luckily, I had our child in PT, OT and speech therapy at Curative and got talking with another mom and she suggested that once we were in the program to ask about music therapy, so we did.
- That's a service your program helps provide. Make a list for incoming families so they have an idea of what they could be using.
- I would say it is a great program that would help your family for the best. They give you a lot of support and make sure that you get enough help.
- Don't rely on this program for essential assistance. Treat it as a bonus when your child receives assistance.
- I think the process has gotten better but still so much paperwork.
- It is worth the wait to get on the waiver program. Take things a day at a time and really get to understand your

child's needs.

-There is such a wide variety of ways that this program can help, it just helps if it is thoroughly explained

Be patient/Wait (7):

-Be patient- the help will be awesome.

-Be patient. It takes time to figure out the best programs/services to meet your child's needs. As your child develops it becomes clearer what they will benefit from most.

-Have patience.

-Be patient and understanding.

-Be patient and be selective.

-Be patient and get prepared early for programs you would like for the next year.

-Be patient if requesting accessibility for home.

Specific Services/Resources (6):

-Play group, social group for families together. Weekend respite.

-For us physical activity.

-Not always clear what all is included.

-Support for before/after school care, assistance with special programs.

-ABA Therapy for any child with Autism.

-Use the respite!

Service Coordinator Support (5):

-It can be hard to make sense of it all, but your service coordinator is there to help.

-Reach out to the caseworker with any concern.

-It takes a certain kind of person to be in this role and it is the kind of person I want to have on my team. There is heart and advocacy that drives it on behalf and with the family with the ultimate goal of healing a family.

-The service coordinators are extremely knowledgeable and truly have your child's best interest in mind.

-Work with the service coordinator.

Parental Payment Limit (3):

-It may be helpful to give an example of how much you could end up paying for "X" amount of service dollars spent.

-I still do not fully understand what I'm paying for on the parent portion.

-Provide an overview of what type of services are available. Explain the financial contribution and that the family is billed a monthly fee for coordinator time whether or not any (case manager) actual services are provided.

Prepare for Waitlists (1):

-Be prepared to be on a long waiting list. Evaluations have happened (speech) for example long waiting list-6

months were told no coverage of any speech services applicable for our child. Why? Because she is on Medicare?

She has a speech and language disorder.

Appendix B

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

Respite Care (25):

- Respite
- Respite
- Respite, options and advice from the service coordinator.
- Respite
- Respite
- Respite #1
- Respite
- Respite
- Respite
- Paying for respite providers.
- Respite
- Having respite available was a blessing.
- Respite care money
- Respite is huge! The struggle we have is not in getting hours to support our family but in finding a consistent provider who is available and over 18.
- Respite hours helped us to find a balance in our busy and challenging family life.
- Respite
- Respite Care
- We really appreciate the respite care
- Respite Hours
- Respite
- Respite care
- Respite
- Respite
- Respite
- Respite is key.

Misc./Other (12):

- Knowing the services available.
- Ask lots of questions.
- Monthly emails.
- No long-term care outside of foster care.
- Community service
- Mentoring programs
- Supply cleaning supplies for my son.
- Help with activities to strengthen gross motor development, socialization.
- Medical
- Yoga
- Therapy community, specialty.
- Midwest Twisters

Adaptive Aids/Special Supplies (9):

- Tomato chair
- The swing trampoline. I am waiting for the night light to help Zach sleep.
- Purchasing items that can be helpful to assist our son in meeting goals.
- Chewlery
- The adaptive equipment that was helpful in keeping my son involved in activities and his peers and family.
- Adaptive aids
- Adaptive bicycle
- Physical therapy aids
- Personal hygiene products for independence.

Waiver/Program (9):

- All services.
- We are grateful for everything, but we like the fast service they give.
- One-on-one understanding of the program and support for our child in need.
- I believe that everything was so helpful with us.
- There is not one department or service they work together, however strongly in their area!
- Information about services, financial support, guidance and support in making it known what services are available, offering their knowledge and support
- The CLTS waiver has been great.
- CLTS Waiver.
- The subsidization of programs and activities. We have been able to get our daughter into programs that have really helped her which we otherwise would not have been able to afford.

Service Coordinator (8):

- Support of our case manager.
- Everything. Our child's needs have changed over the years. The most helpful thing is a knowledgeable service coordinator
- NONE. I spent an UNBELIEVABLE amount of time attempting to set up and communicate with LSS Staff. Emails and phone calls often took up to a week to receive responses and those responses often/usually amounted in to "still in process."
- Our service coordinator, she was very involved and helpful. She was always available and answered questions and responded right away.
- Having a dedicated person definitely helped.
- Specific needs of our child being addressed by the service coordinator.
- Assistance/advocacy during conversations in school.
- Just having a coordinator helps so much.

Daily Living Skills (7):

- The in-home daily learning skills
- One-on-One hours with daily living and skills
- Daily living skills
- Daily living skills
- Daily living skills
- Daily living skills
- Daily living are key

Gym Membership/Swim Lessons (7):

- Reimbursing for swim lessons.
- YMCA
- Gym Membership
- YMCA Membership
- Not enough to support joining YMCA, so Julia can participate in swimming lessons.
- YMCA
- Swim lessons

Music & Art Therapy/Lessons (6):

- Music therapy
- Music therapy with Healing Hands
- Music therapy
- Opportunities for enrichment, music therapy.
- Art and therapy
- Music therapy

Applied Behavior Analysis (ABA) Therapy (5):

- The intensive ABA services were the most beneficial, I feel there is a significant disconnect for the teen years.
- ABA therapy +100%.
- ABA
- ABA has really helped my Autistic son be able to do better in school and function on outings in the community.
- Our BCBA has helped a ton with ideas how to solve problems at school and at home. Also, she is very helpful with IEP's at school.

Camp (5):

- Summer camp.
- Summer camp opportunities.
- Camps for social interaction.
- Camps are good as well.
- Summer camp.

Equine Therapy (4):

- Horseback riding, again not something that was told to our family. I had seen a program on tv and asked our coordinator then I was told by her "oh yeah, we work with other families who use Life Striders, but then I had to call and get put on the waiting list.
- Life striders therapies for autistic children.
- Getting alternate methods of therapy such as horseback riding.
- Horse therapy has been a game changer.

Children's Community Options Program (CCOP) Funding (3):

- CCOP funding should be expanded and booked into the budget.
- My daughter loved 2so we got a zoo pass, and we would love the county to pay for the kind of recreational service.
- CCOP funds for swimming.

Diapers/Wipes (3):

- Wipes.
- The diapers, wipes and pads.
- Baby wipes.

Home Modifications (3):

- Chair Lift.
- Building a fence around my yard.
- Remodel.

Safety Items (3):

- Angelsense
- Door alarms & Jiobit for safety
- Home security

Sensory Items (3):

- Sensory toys covered by the waiver.
- Assists with sensory issues.
- Sensory items: Swing and Bubble Tube.

Social Skills (3):

- Social Skills Group
- Social activities
- Social classes

Subscriptions/Memberships (3):

- Gate signing time subscription.
- The Public Museum.
- Zoo Pass.

Caregiver Support (3):

- Autism educator for my daughter and family to develop goals/tools.
- In-home parent and child support.
- Childcare.

Comprehensive Community Services (CCS) Program (2):

- Helping us get into Comprehensive Community Services

Appendix C

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

Access to Providers/Services (27):

- Respite Providers
- Challenges to find respite providers and services offered in Oconomowoc.
- Help finding respite providers.
- Hippotherapy -It is listed under the state covered services and other neighboring counties pay for it, but Waukesha County does not pay for it.
- Not enough Respite to go around.
- Not enough staff available from a single community of service providers.
- Consulting with a provider.
- Finding the actual respite providers is difficult, I would love more help in finding the actual providers.
- Respite Providers
- Respite Providers
- Respite Providers and highly trained staff for daily living skills, working with the child.
- I would like more help with toys or activities for a child who is developmentally delayed, hyperactive, speech and language developed, etc.
- Car seat delays, support dog denials
- Pay for respite but cannot find anyone to do it. Pay rates for childcare are too low and cannot find anyone willing to do it.
- Having a variety of suppliers if a service is maxed (music therapy)
- Add provider to your vendors.
- Aggressive Autism support, more trained line staff needed. More programs for summer, Christmas break, Easter break, more hours for life skills, training for parents, and IEP's at school's all ages. Parents loose things during IEP's, due to not knowing what to ask for.
- Really need buddy or support programs-to have people do things with him and show him guidance and companionship. Also, friend groups would be very helpful with self-esteem and belonging. Social skills programs for elementary and middle school are hard to come by.
- The only gaps in support occurred one year (2019) when Genesee Community Services failed to find enough caregivers for us and left our daughter with well below half the hours, she needed that year.
- It would be nice if they had social outings or had more information on activities geared towards children with special needs, such as sports.
- Services and items provided are so inconsistent between counties and families don't know what could be covered.
- I was disappointed in a new covered program team Creative Solutions. The communication was not what I expected it to be in a new program and the current struggles I had at home intensified. My need to make this Daily Living skills program work. I really needed better communication about goal delivery and staff. It really became frustrating on my end to communicate what I thought was essential knowledge.
- Music Therapy-Have received one email from Music therapy services of Waukesha after our sons music therapist left the practice. Have had no further contact. I asked the service coordinator to follow up us have received no information-seemed like she was not interested in reaching out about MT services.
- It can be difficult to find staff.
- Social skills programs for elementary and middle school are hard to come by.
- The process to apply for respite care is so daunting that we have never done it. Would be great if that could be simplified or if there was more assistance with completing everything.
- Daily living skills training for minors, vision therapy, educating providers adding good providers, market the program more (to all IEP families in county)

No Gaps (20):

- No
- No, service coordinator is wonderful!
- No
- No gaps
- None
- No
- None
- No
- I cannot think of any. We are good and appreciate the services. Thank you.
- None to report
- No
- We did not experience any.
- In general, I didn't observe any gaps in services/support other than lack of funds
- None
- We experienced no gaps in support!
- Our caseworker has been awesome!
- Our current coordinator is absolutely fantastic! Best we've ever had. She always responds to communications in a timely manner and constantly goes out of her way to provide us the services our daughter needs, often identifying and meeting needs we did not even realize could be met by Waukesha HHS. We adore our service coordinator and appreciate her so much!!
- I do not think there were gaps, everything was so helpful for us.
- Our coordinator was always in touch with us regarding information on when to expect what was available in the meantime.
- Thank you for being here for the needs of our family.

Service Coordination (11):

- Communication
- The turnover in service coordinators. I feel like we are always getting to know someone new.
- I had a very unfortunate experience to have as a contacts people who either do not care to their jobs or are unable to do their jobs. I worked for MONTHS to set up a routine service for my child and accomplished next to nothing It was EXTREMELY frustrating and time consuming. The "gap" rests entirely on the people assigned to our case.
- We have had a few different coordinators in a short period of time, but never felt like were left out in the cold.
- Change over in people.
- My service coordinator seems to change every 9-12 months. There are gaps in communication between the old and the new.
- It would be nice if the case manager actually knew about the resources available in the community. It seems every question I ask does not receive an answer.
- Yes, for a little bit but they met very fast.
- They don't actually help other than financially.
- More information on camps therapies, or things not covered by Medicaid
- Suggesting services that would be useful to my family. With a full-time job and 3 kids I run out of time to find what services are offered and what is available to my son.

Waiting for Services (8):

- Yes, music and we have been on the waiting list for horse therapy for over a year.
- Took forever to get to respite, still waiting on the daily living skills works.
- Work that needs to be done on my son's room. It takes forever for the job to get done.
- Wait time to get on.
- Waiting over a year after bids to get bathroom remodel

- Wait lists for providers.
- Long delays for equipment to help child.
- Long waits for requesting accessibility issues.

Waiver/Program (5):

- You do not tell incoming families anything about services. If we want help with a service, I had to check with our coordinator she has to check with her boss if it is something that the County would help with or not. It would save families if you provided a list like we help with music therapy, art therapy, horseback riding therapy, yoga for toddlers, can your child ride a bike-if not we can help you get an adaptive bike.
- Understanding how each program/service works. Each coordinator explains it differently. There should be 1 script or document that clearly explains what and how a program or service etc. works. Often very confusing when parents are involved with other service programs, insurance, etc. Hard to keep everything straight.
- So many, understanding what to do. Visit ASSEW.com Facebook page pertaining to parent with kids with special needs and autism so many unanswered questions and confused people.
- For an educated person, I felt the process was overwhelming. Assume that a lot of people on the program are confused. I see constant questions in social media groups about what people are getting covered.
- Excessive amount of paperwork to do to request support from outside/ contractors.

Children's Community Options Program (CCOP) funding (5):

- CCOP funding, which should be expanded and booked into budget.
- The gaps occur when funding runs out and does not align with our annual renewals of some programs. In order to stay with the program, we had to purchase it ourselves but are not able to submit it with the next review, so I feel like we are being "punished" for joining later in the year rather than earlier.
- Paying parents through reimbursement is an inconvenience to say the least.
- Not being able to cover services until the end of the year. Running out of funds.
- CCOP Funding runs out too quick.

Misc./Other (5):

- Currently allowing only one community service and eliminating from using support from other service providers.
- School needs books
- Home needs shoes
- The gaps in service is only due to the broken parts of the bigger system. Laws and regulations put ceilings on their efforts.
- There are things we need like a speech/pecs device and stroller but I do not have the capacity to go through the process right now.

Parental Payment Limit (3):

- Your finance department is a mess. We must pay a portion of the services, but bills are not easily understood. If you call and want to talk about the charges and how to figure out the parental payment, they are not straight forward answers. Our payment fluctuates drastically every month and there is no real explanation why.
- We considered dropping out of the program because of the finance department, but then our insurance would not pay for some of the therapies, and they are greatly helping our child.
- Details on the monthly parental payment. I have no clue what I am paying and when I outreached to finance I receive no answer. I receive multiple charges for the same months on different bills.