

2016 Quality Assurance Survey

For the Children's Long Term Support Waiver and Children' Community
Options Programs through Waukesha County

Executive Summary

- ▶ In 2016, **483** surveys were sent out to families who received services from the Children with Special Needs (CSN) unit in 2016.
- ▶ We received **116** total responses.
- ▶ That is a **24%** return. Industry standard return on a mailed, paper survey is 10%. Last year our return percentage was 14.1%.

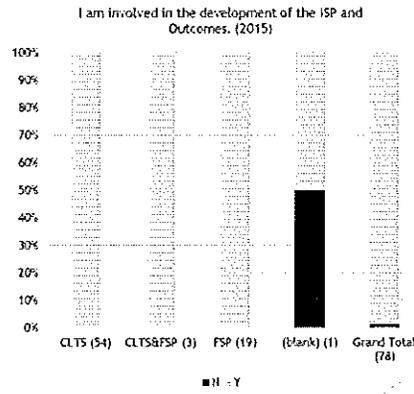
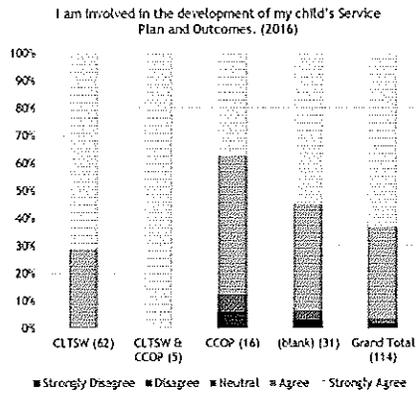
Program Totals

- ▶ Children's Long Term Support Waiver: 62 respondents
- ▶ Children's Community Options Program: 18 respondents
- ▶ Indicated Both programs: 5
- ▶ Left Blank or indicated that they "Didn't Know": 31
- ▶ Total respondents: 116

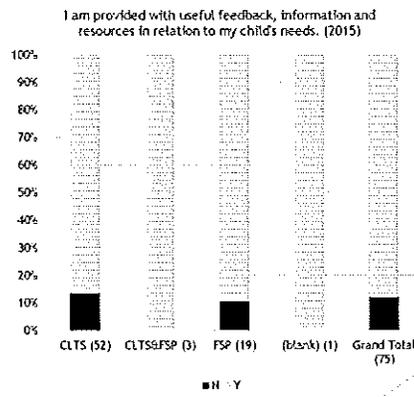
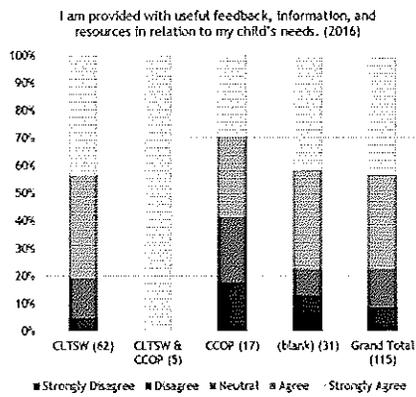
Methodology

- ▶ Families that received services through either the Children's Long Term Support Program or the Children's Community Options Program as of November 1st, 2016 were sent out a paper survey via mail.
- ▶ We continued to collect surveys from November 1st through March 31st, 2017.
- ▶ Included with the survey was a letter on County letterhead that explained the purpose of the survey and our desire to have families participate as well as a postage paid return envelope that indicated it would be returned to a general mailbox "CSN Survey"
- ▶ On the outside envelop we included a red sticker that stated "Information Requested".
- ▶ 2016's survey was updated from the original 2015 survey to include a sliding scale for responses.
- ▶ 5 questions were added to the 2016 survey and some questions were reworded to remove double-barreled questions and clarifying information.

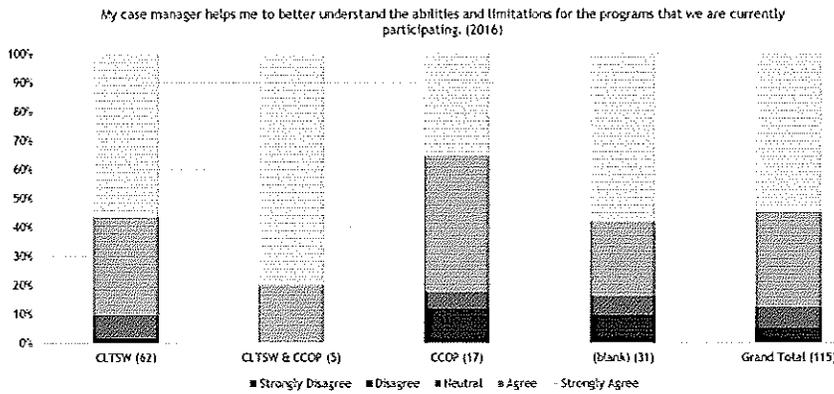
Question 1:



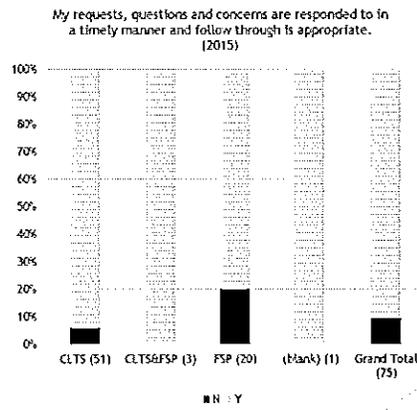
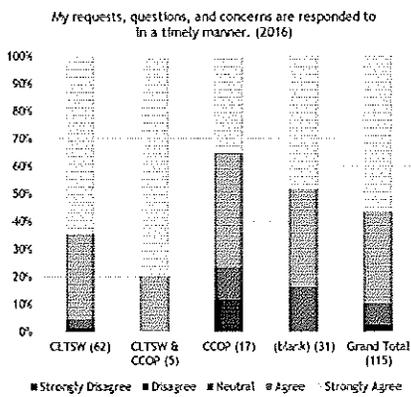
Question 2:



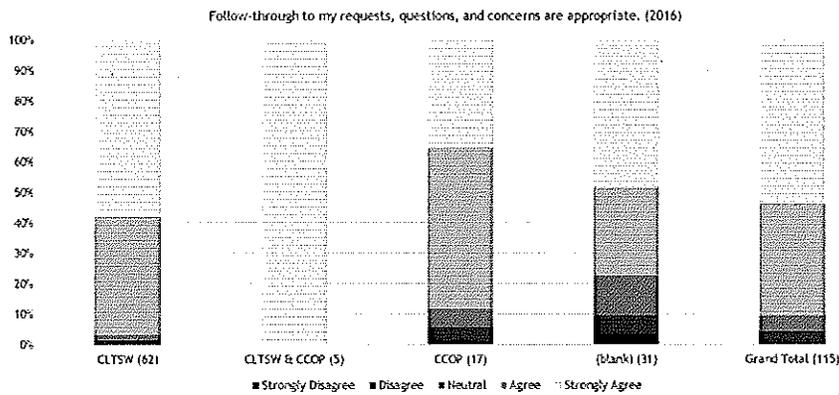
Question 3 (*added in 2016):



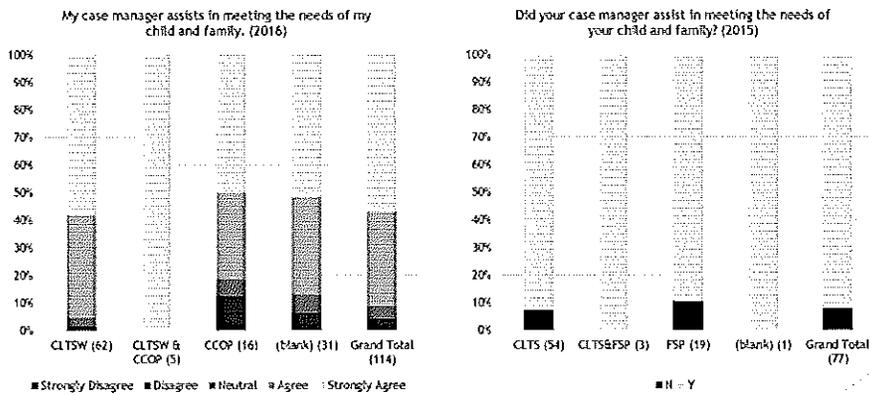
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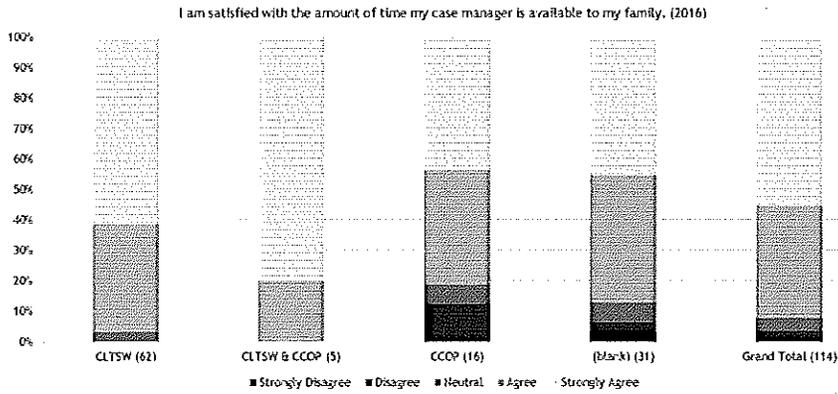
Question 5 (*broken out from question 4 in 2016):



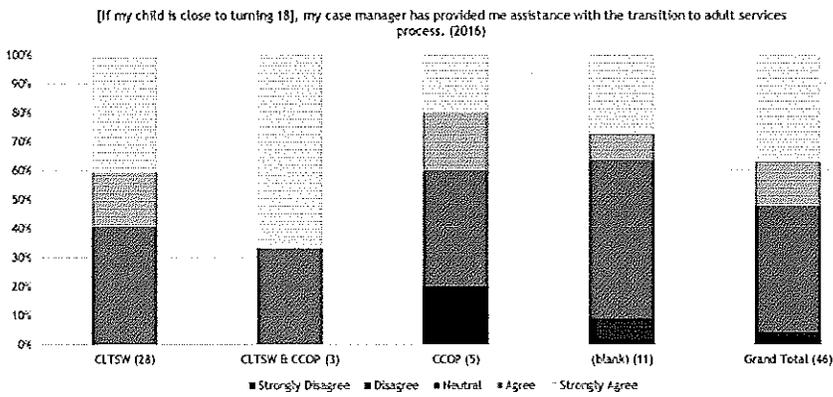
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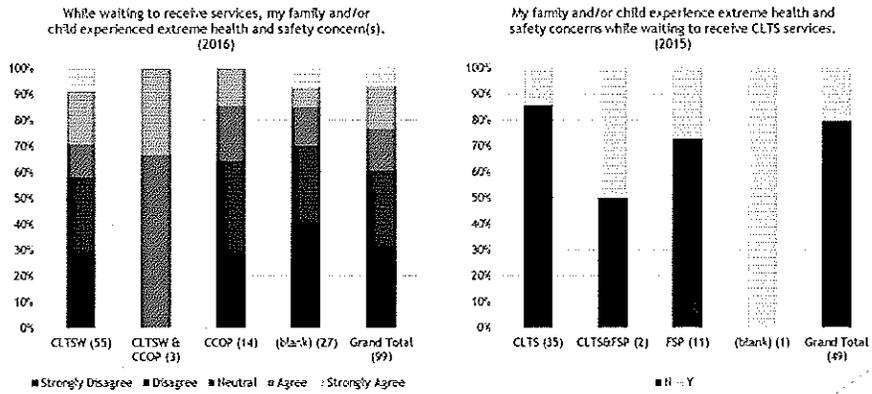
Question 7 (*added in 2016):



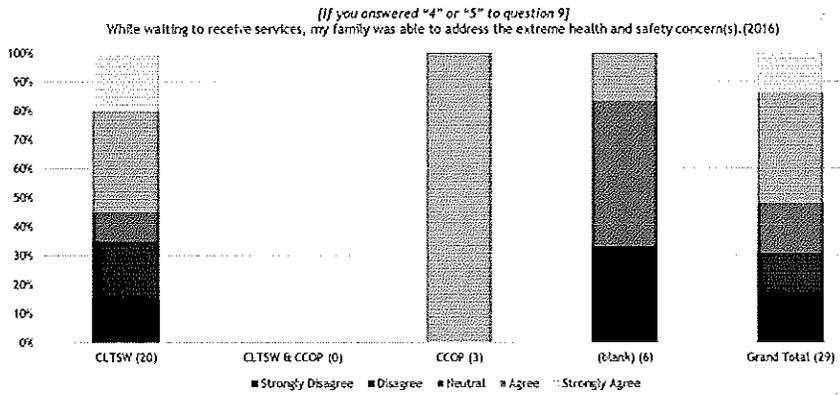
Question 8 (*added in 2016):



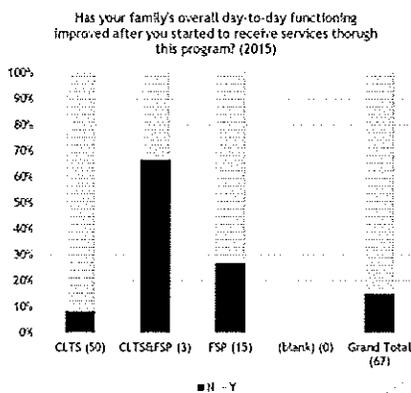
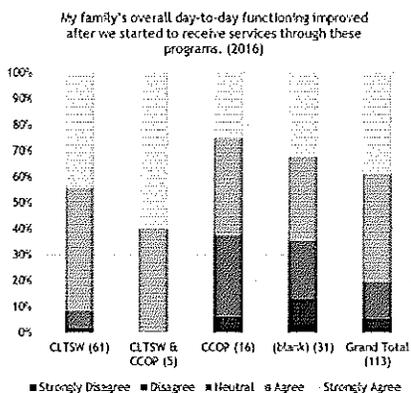
Question 9:



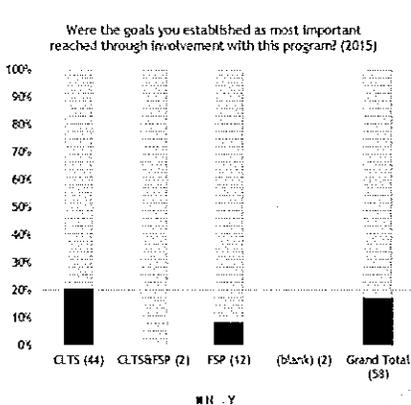
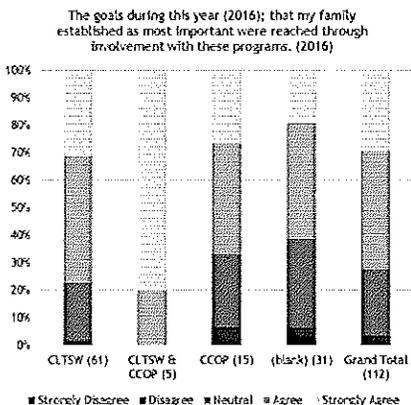
Question 9(a) (*added in 2016):



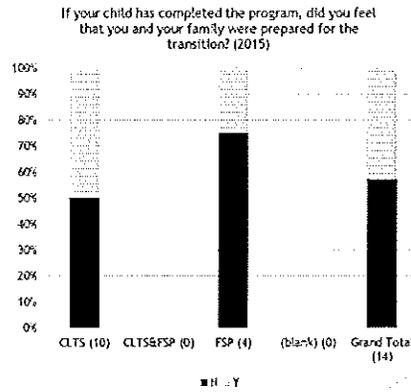
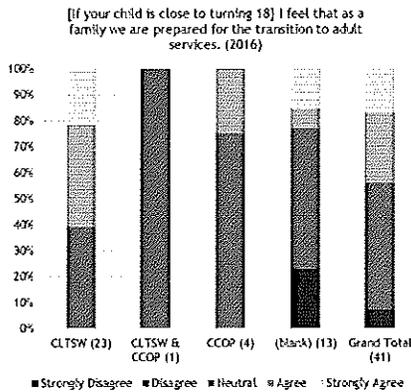
Question 10:



Question 11:

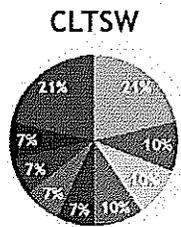


Question 12:



General Comments

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



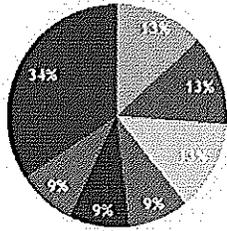
- Ask Questions
- Bounce Ideas Off Case Manager
- Be Patient
- Educate Yourself on Program Services
- Think Ahead - Child's Needs
- Adding Services = Big Change but Worth It
- Not a "Free for All"
- Case Manager is on Your Side
- Misc.

- ▶ Misc. Comments:
- ▶ Always keep an open line of communication
- ▶ Things change all the time
- ▶ Fill out paperwork efficiently
- ▶ Prepare yourselves with research, pray to God and never give up
- ▶ Join parent support groups
- ▶ If something is not working let your Case Manager know
- ▶ Be persistent
- ▶ Don't be afraid to ask for services

General Comments

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

CCOP



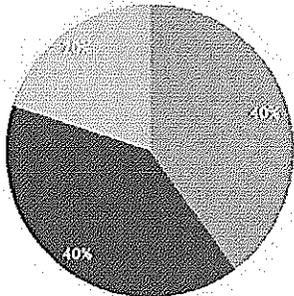
- Ask Questions
- Prioritize Needs Before Meeting
- Wait List is too Long but CCOP Helps
- I Have a Case Manager?
- Patience
- Research What Is Available
- Misc.

- ▶ Misc. Comments:
- ▶ Get on the wait list and check out what it has to offer
- ▶ I have not had contact with anyone for the first 3.5 years since being in Waukesha
- ▶ So many names, programs, resources, I am confused
- ▶ Hard to get mobility items covered due to cost
- ▶ Only gets CCOP what else is available?
- ▶ Great program that our child benefited from
- ▶ Keep open dialog with case manager, they are here to help
- ▶ Advocate for your child's needs by participating in the development of the Service Plan

General Comments

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

Both Programs



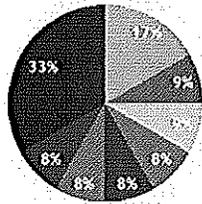
- Ask Questions
- Ask Case Manager for Help
- Misc.

- ▶ Misc. Comments:
- ▶ Have to have patience

General Comments

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

Blank or "Don't Know"



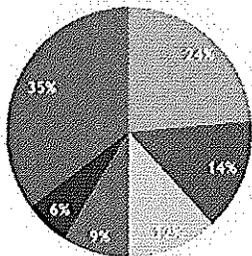
- Use Your Case Manager as a Resource
- The Services Offered - Use Them
- Ask Questions
- You May Be Frustrated By Long Wait List
- Be Sepcific About Your Child's Needs
- Hard To Find Out About the Program (Do Research)
- Be Patient
- Misc.

- ▶ Misc. Comments:
- ▶ Keep all paperwork and receipts
- ▶ Require answers from your worker
- ▶ Do something the child really enjoys as a family
- ▶ Keep documentation of everything, evaluations, resources, school, etc.
- ▶ The program will help you
- ▶ Network with other parents
- ▶ I know that there are lots of hours of work with your child, please keep it up, it will make a difference
- ▶ Understand the politics before first meeting

General Comments

Question 2: Based on your experience, please offer any other suggestions or ideas you may have for changes you'd like to see.

CLTSW



- The Waiver is Limited in What It Can Cover
- More Communication About What Can Be Funded
- More Help with Funding Respite
- More Checking in With Families
- More Transparency with PPL Cost
- Misc.

- ▶ Misc. Comments:
- ▶ It would be nice if Medicaid says your child needs this many hours that your Private Insurance couldn't limit it to less hours
- ▶ Less wait time
- ▶ Please invest in your case managers - ignorant in terms of supporting or advising families
- ▶ Remember that this is not just a job, it requires involvement, service, compassion, and wisdom
- ▶ More access to safety and preventions resources (i.e. door alarms, GPS trackers, locks)
- ▶ Too much paperwork
- ▶ Great Program
- ▶ Eliminate the tax documentation requirement
- ▶ The points of entry are buried/well kept secret
- ▶ If a family has not spent much Waiver funding consider approving items that don't cost much
- ▶ So many changes
- ▶ More funding
- ▶ Become more of a one stop shop for the ASD community

General Comments

Question 2: Based on your experience, please offer any other suggestions or ideas you may have for changes you'd like to see.

CCOP



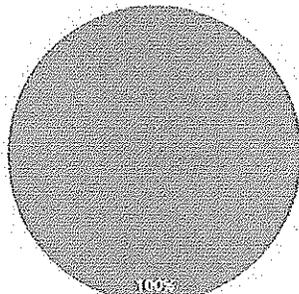
- Clear Up Confusion - Too Much Gernal Language
- Provide List of Qualifying Items
- More Case Manager Involvement Throughout the Year
- Better Communication During Staff Changes
- Misc.

- ▶ Misc. Comments:
- ▶ Let families know when they may be coming up for funding so that they can prepare
- ▶ Keep cases open longer
- ▶ Faster email replies
- ▶ Educate case managers on mobility devices
- ▶ Provide information on where to find funding for items not covered by CCOP
- ▶ Very thankful for this service!

General Comments

Question 2: Based on your experience, please offer any other suggestions or ideas you may have for changes you'd like to see.

Both Programs



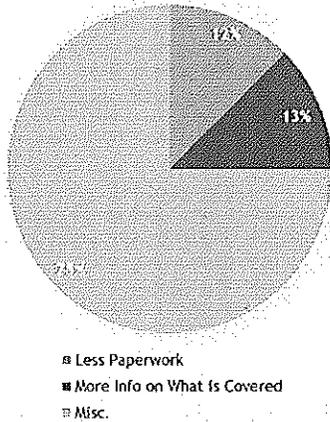
■ Misc.

- ▶ Misc. Comments:
- ▶ Occasional updates via email on the status of services
- ▶ I don't like that my ex gets the same amount of funding for respite when he makes more
- ▶ Great Program
- ▶ A newsletter or paper/email communication including opportunities that may be helpful to our kids
- ▶ Funding Occupational therapy
- ▶ While receiving Intensive Therapy through the State it would be helpful to have funding for sensory items or other things to help at home

General Comments

Question 2: Based on your experience, please offer any other suggestions or ideas you may have for changes you'd like to see.

Blank or "Don't Know"

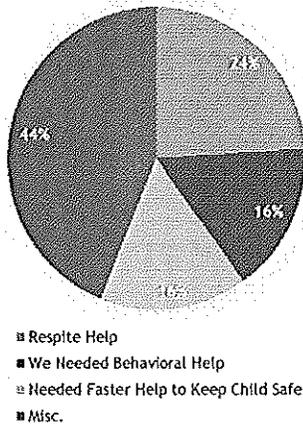


- ▶ Misc. Comments:
- ▶ Stop taking away the programs that support
- ▶ Additional family support from workers
- ▶ Families would benefit from workers knowing resources that are covered through private insurance
- ▶ Options for summer programs (camps) sent out to families in Jan-Feb
- ▶ Info given to hospitals for parents with children with special needs
- ▶ Cover OT, PT, SLP
- ▶ The program is good
- ▶ Have good communication with Case Managers
- ▶ Hold off on transitions from 18-20
- ▶ More providers
- ▶ More respite services
- ▶ Focus on child solving problems themselves at an earlier age

General Comments

Question 3: While you were waiting for services, what was your priority need? What, if any, resources helped you address that need?

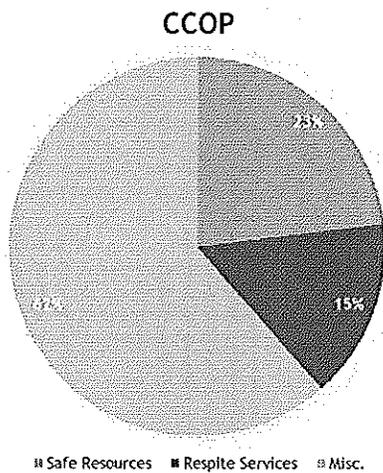
CLTSW



- ▶ Misc. Comments:
- ▶ It was brutal. Families are not prepared to deal with diagnosis
- ▶ Needed ABA
- ▶ Early education through school did not help
- ▶ We received services that our family is grateful for
- ▶ Needed alternative care options
- ▶ Needed new programs
- ▶ Needed more funding
- ▶ Needed personal care coverage
- ▶ Help to fund Peditasure
- ▶ Pediatrician helped

General Comments

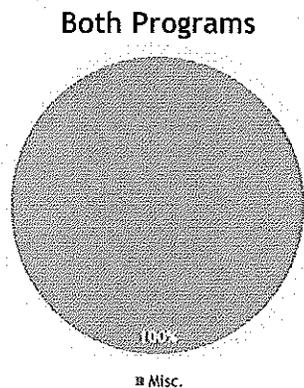
Question 3: While you were waiting for services, what was your priority need? What, if any, resources helped you address that need?



- ▶ Misc. Comments:
- ▶ Needed to make the house accessible
- ▶ What resources?
- ▶ Needed sensory items
- ▶ Critical need was after/off school care
- ▶ Needed larger mobility items for the house and car
- ▶ Needed speech
- ▶ Needed a YMCA membership
- ▶ Needed social/communication development

General Comments

Question 3: While you were waiting for services, what was your priority need? What, if any, resources helped you address that need?

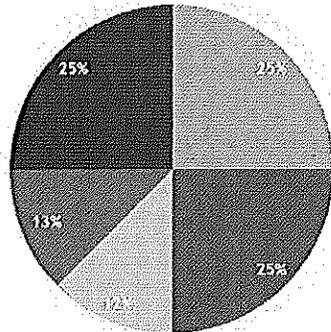


- ▶ Misc. Comments:
- ▶ Needed money
- ▶ Needed therapy hours
- ▶ CCOP helped us "hang in there" during the wait

General Comments

Question 3: While you were waiting for services, what was your priority need? What, if any, resources helped you address that need?

Blank or "Don't Know"



■ Respite ■ Therapy/DLS/ABA
 ■ Case Manager Needed ■ Safety
 ■ Misc.

- ▶ Misc. Comments:
- ▶ Still waiting
- ▶ Private insurance helped
- ▶ If you have no money or too cold make a movie night or game day
- ▶ School support
- ▶ Didn't wait
- ▶ Generally satisfied

Key Points from the General Comments Section:

- ▶ **Advice for parents:** Ask questions, be patient, and use your worker as a resource.
- ▶ **Suggestions for improvement:**
 - ▶ Waiver is limited in what it can fund, provide more information on what can or cannot be covered, and more service options are needed.
 - ▶ CCOP families are asking for more clarification on programs, more contact/support year round from workers, and more information on what can or cannot be covered.
 - ▶ Generally more information on programs are needed in the community.
- ▶ **List of priority needs:**
 - ▶ Safety resources
 - ▶ Behavioral assistance
 - ▶ Respite
 - ▶ High cost items