Question 1. In what parish does your family live?

Sorted Alphabetically

Parish	Frequency	Percent
No Answer	7	1.3%
Acadia	3	0.6%
Allen	4	0.8%
Ascension	5	1.0%
Assumption	3	0.6%
Avoyelles	6	1.2%
Beauregard	5	1.0%
Bienville	1	0.2%
Bossier	28	5.4%
Caddo	61	11.7%
Calcasieu	29	5.6%
Caldwell	4	0.8%
Catahoula	4	0.8%
Claiborne	3	0.6%
Concordia	1	0.2%
De Soto	2	0.4%
East Baton Rouge	12	2.3%
East Carroll	3	0.6%
East Feliciana	1	0.2%
Evangeline	2	0.4%
Franklin	3	0.6%
Grant	4	0.8%
Iberia	6	1.2%
Iberville	1	0.2%
Jackson	1	0.2%
Jefferson	47	9.0%
Jefferson Davis	2	0.4%
Lafayette	19	3.6%
Lafourche	13	2.5%
La Salle	2	0.4%
Lincoln	5	1.0%
Livingston	10	1.9%
Madison	3	0.6%
Morehouse	9	1.7%
Natchitoches	3	0.6%
Orleans	40	7.7%
Ouachita	13	2.5%
Plaquemines	2	0.4%
Pointe Coupee	2	0.4%
Rapides	19	3.6%
Richland	5	1.0%
Sabine	3	0.6%

Sorted by Frequency

Parish	Frequency	Percent
Bienville	1	0.2%
Concordia	1	0.2%
East Feliciana	1	0.2%
Iberville	1	0.2%
Jackson	1	0.2%
Tensas	1	0.2%
Webster	1	0.2%
West Feliciana	1	0.2%
De Soto	2	0.4%
Evangeline	2	0.4%
Jefferson Davis	2	0.4%
La Salle	2	0.4%
Plaquemines	2	0.4%
Pointe Coupee	2	0.4%
Saint Helena	2	0.4%
Union	2	0.4%
West Carroll	2	0.4%
Winn Parish	2	0.4%
Acadia	3	0.6%
Assumption	3	0.6%
Claiborne	3	0.6%
East Carroll	3	0.6%
Franklin	3	0.6%
Madison	3	0.6%
Natchitoches	3	0.6%
Sabine	3	0.6%
Saint Charles	3	0.6%
Saint James	3	0.6%
Saint Mary	3	0.6%
Allen	4	0.8%
Caldwell	4	0.8%
Catahoula	4	0.8%
Grant	4	0.8%
Saint John the Baptist	4	0.8%
Saint Martin	4	0.8%
Vernon	4	0.8%
Ascension	5	1.0%
Beauregard	5	1.0%
Lincoln	5	1.0%
Richland	5	1.0%
Saint Bernard	5	1.0%
Avoyelles	6	1.2%

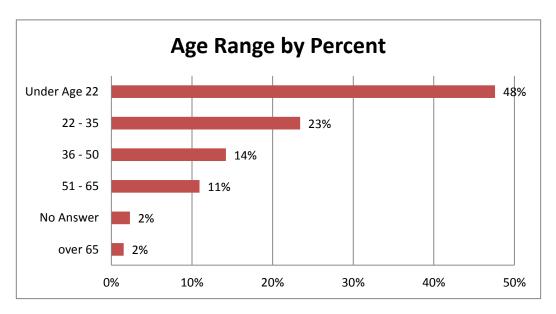
Saint Bernard	5	1.0%
Saint Charles	3	0.6%
Saint Helena	2	0.4%
Saint James	3	0.6%
Saint John the Baptist	4	0.8%
Saint Landry	11	2.1%
Saint Martin	4	0.8%
Saint Mary	3	0.6%
Saint Tammany	32	6.1%
Tangipahoa	24	4.6%
Tensas	1	0.2%
Terrebonne	6	1.2%
Union	2	0.4%
Vermilion	8	1.5%
Vernon	4	0.8%
Washington	7	1.3%
Webster	1	0.2%
West Carroll	2	0.4%
West Feliciana	1	0.2%
Winn Parish	2	0.4%

Iberia	6	1.2%
Terrebonne	6	1.2%
No Answer	7	1.3%
Washington	7	1.3%
Vermilion	8	1.5%
Morehouse	9	1.7%
Livingston	10	1.9%
Saint Landry	11	2.1%
East Baton Rouge	12	2.3%
Lafourche	13	2.5%
Ouachita	13	2.5%
Lafayette	19	3.6%
Rapides	19	3.6%
Tangipahoa	24	4.6%
Bossier	28	5.4%
Calcasieu	29	5.6%
Saint Tammany	32	6.1%
Orleans	40	7.7%
Jefferson	47	9.0%
Caddo	61	11.7%

Question 2. How old is the person with a disability who receives services?

Age Range	Count	Percent
Under Age 22	248	48%
22 - 35	122	23%
36 - 50	74	14%
51 - 65	57	11%
over 65	8	2%
No Answer	12	2%

Breakdown of Under Age 22		
Age Range	Frequency	Percent
Age 5 and under	46	19%
6 to 10	71	29%
11 to 15	52	21%
16 to 21	79	32%

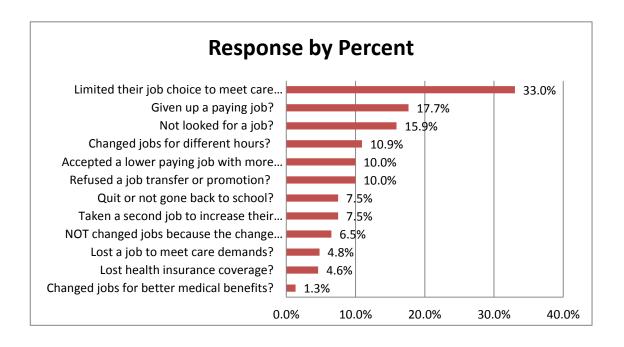


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Question 3. To meet the needs of the person with a disability, has anyone in your household: (Mark all that apply.)

Statement	Frequency	Percent
Given up a paying job?	92	17.7%
Not looked for a job?	83	15.9%
Lost health insurance coverage?	24	4.6%
Changed jobs for different hours?	57	10.9%
Lost a job to meet care demands?	25	4.8%
Refused a job transfer or promotion?	52	10.0%
Limited their job choice to meet care demands	172	33.0%
Changed jobs for better medical benefits?	7	1.3%
Taken a second job to increase their income?	39	7.5%
Accepted a lower paying job with more flexibility, better benefits, or fewer demands?	52	10.0%
NOT changed jobs because the change would have meant losing health benefits?	34	6.5%
Quit or not gone back to school?	39	7.5%

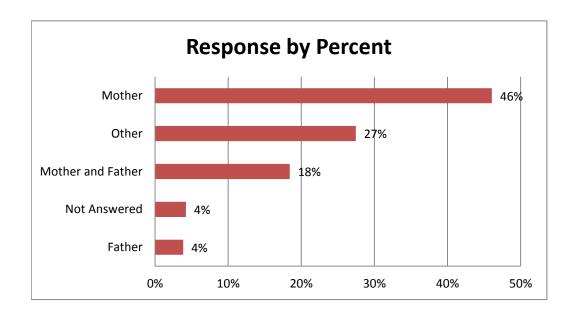
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Question 4. Who is primarily responsible for caring for the person with a disability? (Mark one)

Person(s)	Frequency	Percent
Not Answered	22	4%
Mother	240	46%
Father	20	4%
Mother and Father	96	18%
Other	143	27%

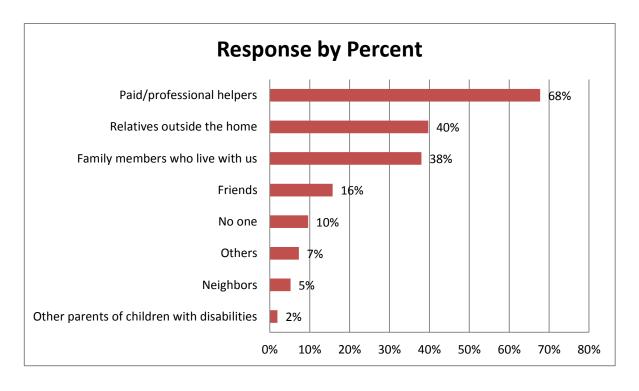
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Question 5. Day-to-day, who is counted on to help meet the challenges faced because of the disability? (Mark all that apply)

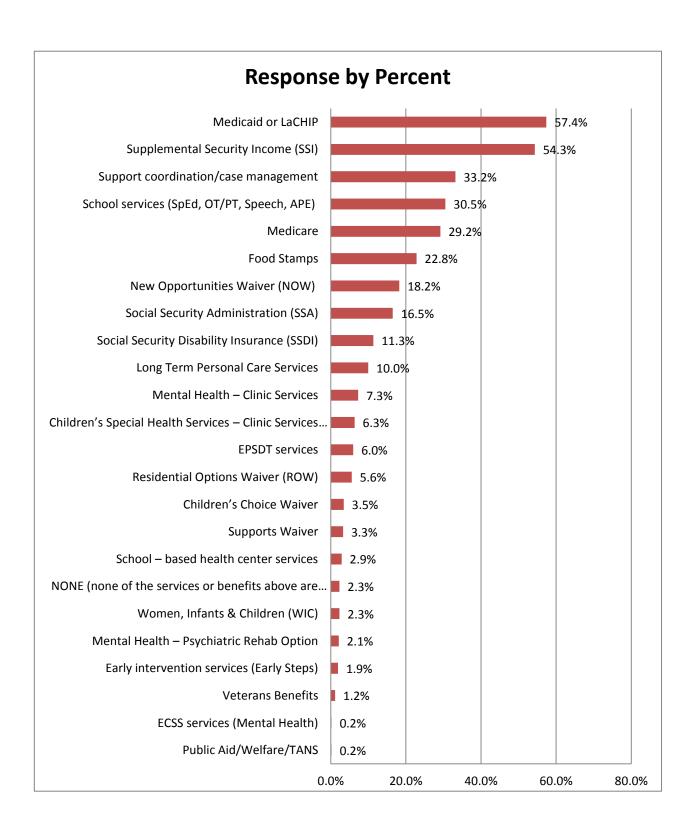
Person(s)	Frequency	Percent
Family members who live with us	198	38%
Relatives outside the home	207	40%
Friends	82	16%
Other parents of children with disabilities	10	2%
Paid/professional helpers	353	68%
Neighbors	27	5%
Others	38	7%
No one	50	10%

n=521



Question 7. Please specify if the person with a disability is currently receiving any of the following services or benefits: (Mark all that Apply)

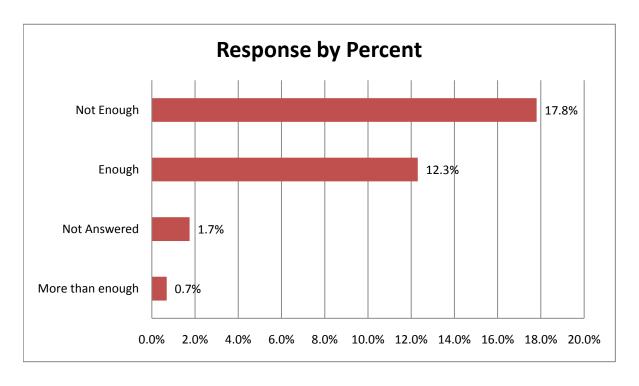
Support/Service	Frequency	Percent
Support coordination/case management	173	33.2%
Early intervention services (Early Steps)	10	1.9%
Children's Choice Waiver	18	3.5%
New Opportunities Waiver (NOW)	95	18.2%
Residential Options Waiver (ROW)	29	5.6%
Supports Waiver	17	3.3%
Long Term Personal Care Services	52	10.0%
Medicare	152	29.2%
Medicaid or LaCHIP	299	57.4%
School services (SpEd, OT/PT, Speech, APE)	159	30.5%
School – based health center services	15	2.9%
Children's Special Health Services – Clinic Services (Screenings, specialized		
therapists)	33	6.3%
Mental Health – Psychiatric Rehab Option	11	2.1%
Mental Health – Clinic Services	38	7.3%
Supplemental Security Income (SSI)	283	54.3%
Social Security Administration (SSA)	86	16.5%
Social Security Disability Insurance (SSDI)	59	11.3%
Veterans Benefits	6	1.2%
Food Stamps	119	22.8%
Public Aid/Welfare/TANS	1	0.2%
Women, Infants & Children (WIC)	12	2.3%
EPSDT services	31	6.0%
ECSS services (Mental Health)	1	0.2%
NONE (none of the services or benefits above are received)	12	2.3%



Question 8. Overall, how adequate is the amount of support you receive in helping you to meet the challenges you and your family face because of the disability? (Mark one.)

Selection	Frequency	Percent
Not Enough	285	17.8%
Enough	197	12.3%
More than enough	11	0.7%
Not Answered	28	1.7%

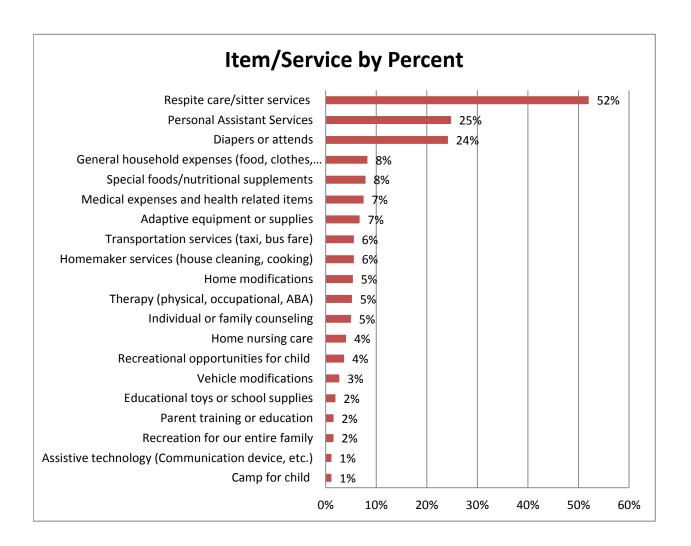
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10a. Please indicate what services you receive: (Mark all that apply.)

Item or Service	Frequency	Percent
Respite care/sitter services	271	52%
Individual or family counseling	26	5%
Recreational opportunities for child	19	4%
Recreation for our entire family	8	2%
Educational toys or school supplies	10	2%
Special foods/nutritional supplements	41	8%
Homemaker services (house cleaning, cooking)	29	6%
Medical expenses and health related items	39	7%
Transportation services (taxi, bus fare)	29	6%
General household expenses (food, clothes, utilities, rent)	43	8%
Home nursing care	21	4%
Therapy (physical, occupational, ABA)	27	5%
Personal Assistant Services	129	25%
Camp for child	6	1%
Home modifications	28	5%
Parent training or education	8	2%
Adaptive equipment or supplies	35	7%
Diapers or attends	126	24%
Vehicle modifications	14	3%
Assistive technology (Communication device, etc.)	6	1%

n=521 (Number of responders)



10b. Are there other supports/services you receive that are not listed? (Please list them below.)

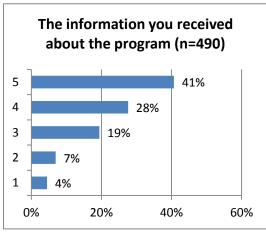
4 hours of PAC each week ABA therapy ARC - Laplace bed Behavioral in-home counseling Behavioral support Blue pads Childcare assistance Children's Hospital Clothes - uniforms Community support team Companion hours for Dec. and Jan worker quit - cannot find a replacement because pay is too low Early Steps Easter seal EDA waiver Educational support Educational toys Family helpers of GNO Fence Food box Food box Food stamps SSI Foodstamps GEHA insurance GEHA insurance GEHA insurance GHA in	Statement
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Early Steps Easter seal EDA waiver Educational support Educational toys Family helpers of GNO Fence Food box Food stamps SSI Foodstamps GEHA insurance GEHA insurance GEHA insurance GHA insurance Hase in home caretaker 8hrs/day 5days/week He has a personal caregiver but I don't know how it's listed. Health create supplies and diapers Health related items like diapers and pads Home of My Own Program House Iget nothing from support waiver, they just ask me to sign a paper every 3 months Iget nothing from support waiver. Interprative services for quarterly meetings Menotr Services Imentor 10 hours a month Mentor Services	Community support team
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Health related items like diapers and pads Home of My Own Program house get nothing from support waiver, they just ask me to sign a paper every 3 months get nothing from support waiver, they just ask me to sign a paper every 3 months get nothing from support waiver. Interprative services for quarterly meetings Menotr Services mentor 10 hours a month Mentor Services	He has a personal caregiver but I don't know how it's listed.
Home of My Own Program house get nothing from support waiver, they just ask me to sign a paper every 3 months get nothing from support waiver, they just ask me to sign a paper every 3 months get nothing from support waiver. Interprative services for quarterly meetings Menotr Services mentor 10 hours a month Mentor Services	Health care supplies and diapers
get nothing from support waiver, they just ask me to sign a paper every 3 months get nothing from support waiver, they just ask me to sign a paper every 3 months get nothing from support waiver. Interprative services for quarterly meetings Menotr Services mentor 10 hours a month Mentor Services	Health related items like diapers and pads
get nothing from support waiver, they just ask me to sign a paper every 3 months get nothing from support waiver, they just ask me to sign a paper every 3 months get nothing from support waiver. Interprative services for quarterly meetings Menotr Services mentor 10 hours a month Mentor Services	Home of My Own Program
get nothing from support waiver, they just ask me to sign a paper every 3 months get nothing from support waiver. Interprative services for quarterly meetings Menotr Services mentor 10 hours a month Mentor Services	house
get nothing from support waiver. Interprative services for quarterly meetings Menotr Services mentor 10 hours a month Mentor Services	I get nothing from support waiver, they just ask me to sign a paper every 3 months
Interprative services for quarterly meetings Menotr Services mentor 10 hours a month Mentor Services	I get nothing from support waiver, they just ask me to sign a paper every 3 months
Menotr Services mentor 10 hours a month Mentor Services	I get nothing from support waiver.
mentor 10 hours a month Mentor Services	Interprative services for quarterly meetings
Mentor Services	Menotr Services
	mentor 10 hours a month
	Mentor Services
nentoring	mentoring

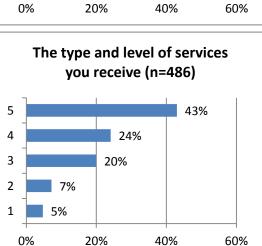
MITS	_
more respite hours	
OCDD	
OCDD	
OCDD	
OCDDS	
pay additional respite out of pocket	
PCA BEFORE NURSING HOME	
Personal Care Attendent	
Personnel care attendent	
Psychiatric	
rental assistance	
Respite ccare Center-24 hour care wknd like lafayette ,la	
Respite/PCA care	
Sign language training for 1 direct support worker	
Sitter from community "Family's First Choice" support team counseling once a week	
speech therapy	
spouse receives SIL benefit from services	
SSI	
summer program	
support hose	
support services	
Supported work	
Synergy home care	
They just ask me to sign a paper every 3 months	
Transport her to work	
trying to get power chair	
tutoring	
Utilities and cable	
wheelchair repair	
Wheelchair repair	
Wipes	

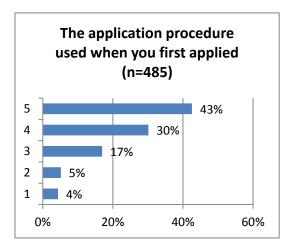
Question 10c. For each area below, circle the number that best describes your level of satisfaction with the service.

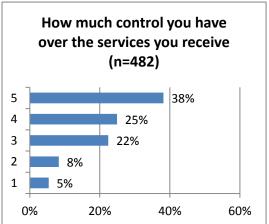
1 = Not at all satisfied, 5 = Very satisfied. (Circle only one response per area.)

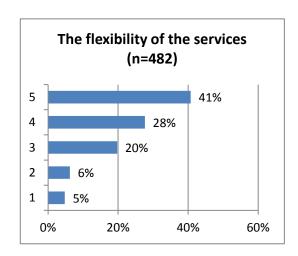
How satisfied are you with			Score							
Statement		1	2	3	4	5	Mean			
The information you received about the program	Frequency	22	34	95	135	199	3.7			
(n=490)	Percent	4%	7%	19%	28%	41%	3.7			
The application procedure used when you	ion procedure used when you Frequency 21	21	25	82	146	206	3.7			
first applied (n=485)	Percent	4%	5%	17%	30%	43%	3.7			
The type and level of services you receive	Frequency	23	35	97	117	209	2.6			
(n=486)	Percent	5%	7%	20%	24%	43%	3.6			
How much control you have over the	Frequency	26	40	108	120	184	2.5			
services you receive (n=482)	Percent	5%	8%	22%	25%	38%	3.5			
The flexibility of the services (n=482)	Frequency	23	30	95	133	196	3.6			
	Percent	5%	6%	20%	28%	41%	5.0			
The way you have been treated by people	Frequency	10	14	50	102	312	4.1			
involved with this program (n=493)	Percent	2%	3%	10%	21%	63%				

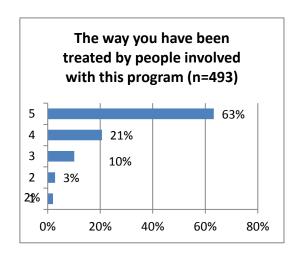










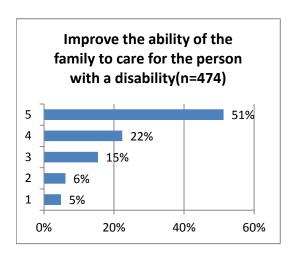


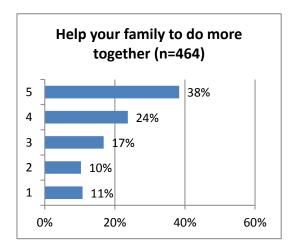
Question 10d. For each item below, circle the number that best describes the impact these programs have on your family.

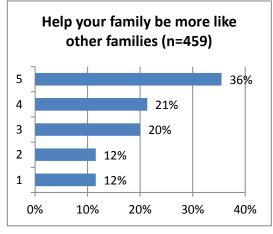
1 = No impact at all, 5 = A lot of impact. (Circle only one response per area.)

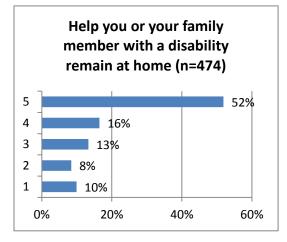
How much do these services/supports		Score							
Statement		1	2	3	4	5	Mean		
Improve the ability of the family to care for the	Frequency	23	29	73	106	243	4.2		
person with a disability (n=474)	Percent	5%	6%	15%	22%	51%	4.2		
Help your family to do more together (n=464)	Frequency	50	48	78	110	178	3.8		
	Percent	11%	10%	17%	24%	38%	5.6		
Help your family be more like other families	Frequency	53	53	92	98	163	-1 27		
(n=459)	Percent	12%	12%	20%	21%	36%			
Help you or your family member with a	Frequency	47	40	63	78	246	3.9		
disability remain at home (n=474)	Percent	10%	8%	13%	16%	52%	3.3		
Reduce stress in your family's life (n=476)	Frequency	39	38	81	116	202	3.9		
Reduce stress in your family's life (fi=476)	Percent	8%	8%	17%	24%	42%	3.9		
Allow you or your family member to work (n=451	Frequency	109	32	64	77	169	3.5		
	Percent	24%	7%	14%	17%	37%	3.3		
Help you or your family do things that you were	Frequency	48	62	78	90	191	3.8		
unable to do before (n=469)	Percent	10%	13%	17%	19%	41%			

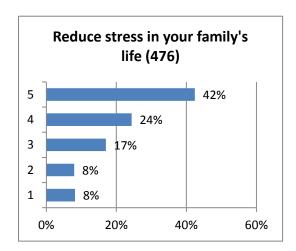
n=781

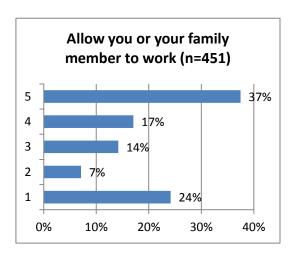


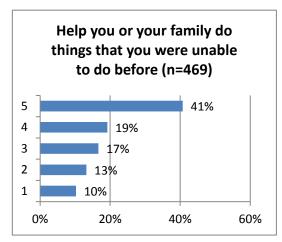












Question 10e. What do you MOST appreciate or value about the Individual and Family Support program?

Statement

A bit of help - but not enough hours for me to keep a real job

Ability to do things as a family

Ability to ensure my son is cared for, interacts with others outside our home, learn independent skills, which allows me some ability to care for other children's needs.

Ability to work and rely on someone to take care of my son without me having to worry

Able to choose a respite worker I am comfortable with. Able to have small amount of time to run errands or work longer

Able to do more personal care

Able to do things and go places I couldn't at first

Able to get personal care attendent so I can remain in my home

Access to psychiatrist

aid, respect, care and pampers

All the help

All the help I receive.

All the help in general

allow both parents to work therfore able to provide a handicapped modified home and ability to pay for medical products/supplies not covered by medical insurance

allows her to be home and family to spend time with her, and she gets out more

Allows me more personal care for my family member.

Allows me some alone time, and for my child to be more indpendent

Allows me some free time

Allows me time to myself

Allows me to attend church, shopping, and other outside activities

Allows me to feel comfortable going to work and knowing that someone is taking care of my son

Allows me to get the help I need

Allows me to spend time with my husband

Allows me to take care of chores/duties outside of the home

allows me to work and hire a private sitter, which is needed bc of health issues

Allows my son to participate in group activities

Allows PCA to take care of my child so that I can work

Always available whenever I need them.

Always there when we need them

Anthony has a mentor

Antonio has a mentor.

appreciate the ceiling lifts, the sitter, the kindness if I ask for help

appreciative of some respite care

As her primary caregiver, it allows me to feel less stressed and to have some time for myself.

As primary caregiver, it allows me to feel less stressed and to have some time for myself

As primary caregiver, it allows me to feel less stressed and to have some time for myself

assistance is appreciated

Assistance w/rspite care and zoo membeship for our family. This helps out tremendously

Assistance with diaper expenses

Assitance with respite care and zoo membership for our family. This helps out tremendously.

Been so helpful to us. We recommend them very highly.

Being able to afford special foods/nutritional supplements

Being able to have a sign language direct support person and interprative sign language

Being able to know she is cared for when I go to work

being able to purchase personal care items

caring individuals who really try to assist in making life a little easier with sitter services and paying for certain handicap equipment

Case manager

case worker (she is wonderful)

case workers are supportive and helpful

contact from coordiantor, assistancec with support for childcare services

Coordinators are genuine in their effort to provide support, have been helping me for nearly 20 years

coordinators are very loving and understanding

David has someone to take him on age-appropriate outings.

Easy to communicate with our local office and have face-to-face relationship

ehlps my brother to live a somewhat normal life, program provides diapers that are gretly needed

eliminating costs of purchasing diapers and wipes

Enables me to work and run errands.

Erin enjoys being with worker because of age.

Everyone has been so helpful and polite.

Everyone is super nice and always polite, answer all of your questions with respect.

Everything

Everything

Everything

Everything

Extra financial support, wouldn't be able to continue therapy without it

Family member is bed-bound and unable to communicate or move on his own.

Financial assistance

Financial assistance helps defray "some" of expenses incurred since mental handicapped individual moved and became a member of our household.

Financial assistance when living on fixed income/choice to choose your caregiver.

Finding a person like Brenda Dunlap who is genuine, listens, cares, and tries to help

Flexibility

Flexibility and peace of mind it affords

Flexibility and wide range of support

Flexibility of choosing care given

Flexibility of choosing care given

For respite care, you can choose the sitter so it is someone you trust

For the school uniforms and the respite it gives the family time together. I'm grateful for all the services.

Freedom to be in my own home under care from people who really care and help me

Freedom to do more and feel my child is safe at home

getting help to care for my child

Getting help with diapers, pads, etc

getting to know the support coordinator to build a better rapport

Given primary caretaker time for self and to not be so stressful

Gives me a chance to relax, helps pay bills

Gives me the choic of who will be w/my child and it enables me to have a little time to get other things done.

Gives me time to spend time w/other kids

Gives my daughter opportunity to socialize

Gives the family a little free time

Glad there is a program like this in the community

Glad there is program like this in the community because some family just isn't together when you lose someone in family that is when program comes in to help.

grateful for what we receive

Hap House

Has given my son back his independence

Has helped us pay for respite/sitter services where we otherwise wouldn't have been able to pay

Has reduced my stress level in dealing with my son

Have some me time and knowing Shannon is with someone who cares.

having a dependable person to care for our son while mom took care of self and husband when we were ill

Having a worker to bring me to visit my wife in the nursing home

having additional person provide training of basic life skills-greatly relieves stress of this area

Having help w/lifting, general load/cae of a speial needs cild. The respite is very helpful

Having some funds for PCA allows us to work and my son to get to therapy.

Having someone to help with the lifting, general load/care of a special needs child. The respite is very helpful.

He is learning self help skills and I have 2 other children that I participate in their activities.

Help and assistance

Help for doctor's appointments for primary caregiver

Help live a more normal life

Help live a more normal life

Help provided allows me to take care of obligations more effectively

help w/transporation of disabled family member

help we receive

Help with paying for sitters while parents work.

Help with school uniforms and community support team

helps a little to reduce financial stress associated w/therapies required

Helps budget by providing money for needed nutritional and hygiene supplies, also respite for sleep

Helps child do extracurricular activities

Helps give us a break

Helps Lisa to live a more normal life

helps me pay for things that insurance won't

Helps me so much

Helps my granddaughter have personal independence

helps relieve financial burden

Helps relieve stress

Helps single parents

Helps us get the breaks we really need

Helps us to understand things that we didn't before, English is our second language

Helps with expenses

helps with our needs

Helps with respite care so I can go to work everyday. Also helps with diapers.

helps with the sitter so I can work

Her case worker is always available and she helps in anyway she can

How concerned they are about the recipient.

How nice the people are

I am able to hire someone to take my son to and from work, basketball practice, other outings and appts

I appreciate attentiveness/persistence; also love their caring/emotional attachment to our situation

appreciate attentiveness/persistence; also love their caring/emotional attachment to our situation

I appreciate having someone I can call when I need help making choices that will affect my life

I appreciate it when program staff understand the disability and the needs of that person with specific disability.

I appreciate Ms. Rosland Nelson, she answers all questions, shows up when she says. Always professional, doesn't talk down

I appreciate the \$150 he is allowed for diapers and pads as the two costs \$218 a month.

I appreciate the assistance for PCA services which enable therapy sessions to be considered more consistantly.

I appreciate the diapers so much and his caregiver is so wonderful and dependable.

I appreciate the fact that I chose who cares for my child and the fact that he can remain at home

I appreciate the help given to my brother that saved him from being operated on

I appreciate the help the worker put in to assist to make this possible for the family to keep life simple.

I appreciate the pull-ups that are provided. She can be changed more often because of them.

I appreciate the time and effort from every staff member

I can go to run errands the three days the sitter is there, a lot of relief

I could not afford to pay anyone to help me care for my sister

I do havea on and off moment by myself

I don't understand the program

I feel the support has helped my family do other things as a family that we were not allowed before the services.

Every little bit of financial support helps us.

I have learned by weakness dealing with I;my diabled child.

I have qualified personnel to care for my sister and she is able to live in her home

I have two that require 24/7 care. It has helped reduce the stress and enable me some personal time.

I like the service from the respite care, as well as the behavioral/educational supports.

I love program. They help me out.

I think it is a very good program.

I use the services to help when I have to work and there is someone here to take care of the person.

I value their loyalty to the program and how they keep the family informed on changes in the program.

la ppreciate their attentiveness and persistence. I also love their caring and emotional attachement to our situation.

if it were not for these programs people with disabilities would still be outcast

I'm a single mom. It saved my family.

Independent choice to pick an outside caregiver and flexible days and hours through the respite support we receive

It allows my husband and I to have a break without our children and strengthens our relationship.

It allows my wife time for her personal needs

It could be better. We move here from Denver and Maryland and their programs are more better.

It eases the burden that is put upon myself and others in places like mine. My son likes me to be home with him.

It gives me a chance to have time for myself

It gives me time to spend with the other kids when I have someone else there to help with Charlie.

It gives us a break

It has been a big help to us, wouldn't know what to do without the program

it helped me get out of the house and make a little money to help out

it helped reduce some of the financial stress with raising a disabled child

It helps me our on the care of my child so I can focus on my household.

It helps me out on the care of my child; so I can focus on my household

it helps me to be able to do more things with my niece

it helps me to pay for a sitter to continue working

It helps us give our son the best care possible

It helps when it helps.

It helps with a part of household expenses.

It helps with our family member

It is wonderful

it lets me have independence

it lightens my load some

It proves that other people do care.

It reduces stress

It reduces stress

It relieves a lot of stress

it takes stress off of me and helps Trellanie to be independent

It's a lot of help and I thank you for it!

Kim Fontenot & Troy Abshire have been extremely supportive and have provided tremendous support for my child and me. I was able to go back to college.

Kindness and support we receive

Learning to do things she has never done

Listen and care how keep son in home environment.

Living at home with family

Loving people

Mental and physical relief

Money

Money to pay for ABA therapy

Mrs. Noyokie Brown

My agency Dream Team

My daughter is able to be with other young adultsw every day at the ARC and gets to attend social occasions as well.

my husband can get the supplements that medicaid does not pay for

Nice knowing we have someone coming to our home who can help watch our son. He has seizures all the time.

OCDD has been supportive in many stressful & confusing times and decisions.

Open communication; accessibility of otherwise expensive undergarments; empateticto futile life-long battles caused by autism/incontinence

open communication; accessibility of otherwise expensive undergarmets; ampathetic to futile life-long battles caused by autism.

Option to choose PCAs

Ability to leave house without worrying about my daughter. Knowing she is cared for.

Our case worker at OCDD is always willing to help find materials/activities/programs to help our child

Our life was hectic & chaotic befre our respite, now we have some sanity

Parents of disabled person are senior citizens with health concerns, helps with taking him out in the community or caring for him for parents to keep Dr.'s appointments

pay 1 day a week for a babysitter

pay bills & grocery shop

payments for PCA help me to have a job as a single mother and support my family

PCA Services

Professional attitude, explanation of benefits and services

Really helps out on diapers

Reduces stress and allows us to go places when we need to work or visit family

Reduces stress, allows us freedom

Relieves a lot of stress

Relieves stress

Relieves stress to know that my child is being taken care of while I'm at work

Representative we work with does what she can to help and is very kind

respite

Respite

Respite allows me to spend time with my other 2 children

respite allows us to attend events that he wouldn't tolerate

Respite care

Respite care hours

Respite care my son gets because its helping him adjust to daily living more and trying to become more independent

Respite helps me go back to school, nutritional support helps me be able to pay my bills

respite hours to do family things

School uniforms

She goes to the vocational program, and they teach her different activities.

Since client is totally dependent on others he can now go places with the assistance

sister/caretaker able to get hours for brother

Some help (even though only little amount) is better than none.

Someone helps every other day for three hours not on weekends

someone is able to be there when I am not

Someone to help

sometimes I can stay home and rest or do something I couldn't otherwise do

Staff is knowledgeable about services, customer friendly, patient

Support coordinator's attentiveness, support and info offered

Support from others, impact on life

thanks for the assistance

thanks to OCDP from the Bondi family

That I am able to choose a respite worker I am comfortable with. I am able to have a small amount of time to run errands or work longer.

that I can have someone here so that I can be able to work

that I can keep my family member at home, work and not have to put them in an institution

That I know my child is looked after when not in school.

That I'm offered info about what's available for my child

That it lets my daughter live in her own home, which she has wanted for many many years.

That my child is able to be in an environment whre preofessionals understand him and his needs and he's not forced to conform to standards he can not meet.

that my son receives 40 respite hours a month

That someone comes in and works with her

That someone comes to be in the home while we are at work

That someone comes to help with her bath

That someone is there that I can talk to and get from.

That there is assistance being given - I am a single parent

That they call on a monthly basis

That they explain things well and very understandable.

that they have concern for the disabled and their family member also

That they're always there when I have questions and are very understanding

That you can call them when in doubt of anything and that we can have our brother home daily.

The 10 hours a week allow me to run errands while my son benefits from the services

The 20 hours/month helps. Just could use more respite care to run earrands each month and work.

The ability to attend work on a full time basis.

the ability to keep my full time job and still be able to take care of my son

The additional help in my home

The additional help in my home

The additional help in my home.

The assistance

the assistance with entergy and increase my quality of life

the break it gives me is invaluable to my mental health, caregivers is a social event to my daughter

the care and concern given to us

The care and support from the office of OCDD.

The care the case manager brought forth to provide my family with services.

the caring and professionalism of the team

the caring attidtude of the staff

The caring demeanor of her worker.

the caring professionalism of the team

the caring professionals

The choice of who I am able to allow to stay with my son.

The effort my worker puts in

the ensure

the extra income helps to pay our sitter for a few more hours than we could afford

The financial aid has truly been a blessing. The respite allows us to get away or even just go to the grocery or to a movie. We appreciate every penny.

The financial help

The freedom for her to stay in her own home.

The friendliness and helpfulness of all staff members at OCDD Region 6. They are all wonderful people.

the help

the help

The help

The help given, so I'm able to take care of outside duties, chores

the help gives me time to do things with my other family members

The help in communicating in the community

The help in communicating in the community.

the help is great

The help is great.

the help is needed

the help received

The help they give with the sitter

the help to try and make things better for my daughter

The help we receive when there is an emergency

The home modifications

the little respite it provides

The money help pay for sitters.

The money helps pay for sitters.

The money we receive back for a return or help for my sons medicines.

The only service I receive regularly for my son is help paying for a sitter. This is a tremendous help to maintain my personal well being.

The opportunity to spend small amounts of time with other 2 children.

The opportunity to spend small amunts of time w/other 2 children

the opportunity to work

The oppurtunity for others to help as much as possible; my sister is not the easiest to handle.

The PCAs are genuine land considerate.

the people

The people are caring and supportive

The people are so caring and do all they can to meet our needs

The people I have talked to and dealt with were very helpful and understanding about our child.

The people I talked to and delt with were very helpful and understanding

The people I talked to and delt with were very helpful and understanding

The people who are there to help us.

The people who are willing to help and support us

the people who interact with us are kind and dedicated, appreciate the stipend

The people who run it

The personal touch

The program is fine.

The programs and workers are very helpful

The respite care it gives family members and having someone to lift patient

The respite care it gives my family members and having someone to lift patients.

The respite servcies

The respite services help me get my child to doc appt/give me some free time to myself

The respite services help me to get my child to doctor appointments and gives me some free time to myself since I have no family help.

the services provided an opportunity for my teenage daughter to socialize with others outside the family unit,

The services that provide a supplement for childcare so parents can work outside the home

The staff

The staff are kind, considerate of my child and really want to help meet our needs.

the staff's support and help at anytime. Explain things in a good manner

The support it gives

The support services and assistance provided to Christopher is always met when needed.

The time my sister gets when someone can give her one on one attention and for her to get our more.

the time they give me for someone to come in and help me care for my son

The time, care and effort of the person who cares for my child

The way that they care about you

The way the services has help my family life quality; it also help my son's behavior in the public and at home

The way the services have helped my family's life quality and it has helped my son's behavior in public and at home.

The way they help you with anything and give you info about things that may help you.

The workers are very compassionate and meet their client's needs. He is relaxed more because he is going outside the home with others.

Their attempt to help "normalize" our family life.

Their help for me and my family

There is some available for when I can't be there. They do things that free up my time for more quality time with him

They are always on time

They are there for both our needs.

they are very caring, very eager to help us in any way

They are very compassionate caring people. They always listen to me and my mom. They always call back with any answers we might need.

They call to check on the persono and help us to understand any paperwork we do not understand

They care

They care

They have been a real help in need.

they have some people that care about the disability person

they help me to stay in my house and live on my own. How quick they respond to me when I call

They help the kids that need help.

They help w/diapers, pads, swipes, saves on a lot of washing.

They pay someone to help with my son.

They provide a job for him which help him live a normal life

They provide a job for him which helps him live a normal life.

They were there for me when no one else was able to help

They're very polite and compassionate.

They're very respectful and really care

This program enables me to keep my son at home where he is most comfortable and happy

time for myself

To be able to talk to support

Treatment for autism is so expensive and we were able to get a therapy specialist over the summer and continue some ABA therapy.

Understanding and caring

understanding/caring of worker

utility assistance for ventilator dependent child

Valuable to have individual and family positive behavior counseling

Very good

Very happy with all help provided

Very helpful

Very helpful, able to remain in community.

Very well pleased

We appreciate the understanding of the needs and amount of care required to give the best care to our daughter.

We can act like a regular family.

We can afford a sitter more frequently

We do more things together and he's learning as he goes along.

We don't have to buy most of the supplies that I need.

We get 5 hour a wk which is better than non at all but we get no support from case management and we are still on our own seeking help

We have someone who cares

When we need help they are there for us and our child

Without it, could not afford help and don't know what would happen then.

You all are kind and understanding

You can call in and get a response.

10f. What would you do to change how the Individual Family Support program is run?

Statement

A mature male person for the weekend to spend quality time for a role model

a more indept intake process to help access needs and more inforamtion about the array of services provided

Add more hours for help.

Affer more than 1 assistance program at a time.

All is well; keep doing for others what you are doing; you will be blessed for it.

Allow family members to be PCA. It hard to find good, reliable care... - someone to trust to be in your home & care for your child

Allow family members to be PCA's - I feel more comfortable w/some I trust and know. They will care for & love my daughter & give her the best care. Its very hard to find good workers.

Allow family members to be PCA's.

Allow family members to be personal care attendents. It is hard to find good, reliable care...someone to trust to be in your home and care for your child.

allow more hours of care. In the summer she needs someone with her 24 hours a day because she has seizures

allow more hours to needy families

Allow us to use sitter more frequently on some months than others

assistance for other therapies presently paying for out-of-pocket

Assure each staff member is knowledgable of disabilites and families are knowledgable of ALL services.

Base it more on practical need and less on "amount" of household income.

Be made more aware of services that are available, staff who seem happy to serve

Be more receptive to the changes of individual's needs

Be more receptive to the changes of individual's needs

Being constantly under the cloud that services may be cut, hours cut or money cut.

better funding across the board, Need someone to research grants that are available for individuals and the entire program

Better qualified workers

better specialized training, more hour of help

better training for helpers, more hours of help

better treatment by staff

Case management

Change how the amount of money given to each household is calculated

Change some of the attitudes of some of the workers. They need to be more understanding.

Change the law to prevent these agencies' budgets from being slashed

Choose a caregiver age group according to the child's age.

clearer info about what programs are available and how or why they apply toour situation. More communication between agencies and more case workers-Do not cut more employees

Companion hours are not utilized because it is impossible to find someone willing to work at those wages and with autism. There is no future, no beneficial care, no way out of the mazethis diabiliyt has us in. Without I.F.S. I do not think I could go on, much less have any faith in facing each tomorrow

Companion hourse are not utilized b/c it is impossible to find someone willing to work at those waes and w/autism. There is no future, no beneficial care, no way out of the maze this disability has us in.

cut down on the paperwork, our services were interrupted b/c of delayed paperwork

Daugher needs more services but I cannot get them due to income

definitely need emergency hours not for weekly use but for when one parent is ill/hospitalized and both parents need to be away from person with disability for short periods of time

Direct deposit for checks and internet based reporting

Distinguish between mental and physical disabilities. Pay accordingly

Do away with waiting lists

Do more to recruit and maintain workers in a rural area, more training

Doing a good job.

Don't know. Just would like to know that all of the individuals needs are addressed an that the families needs are considered; as the result/impact of decisions made.

Don't leave it up to OCDD to determine final eligibility - doctor should decide, not a worker

Educate staff, get more workers, stop cutting community based programs

efficiency/less tape

Ends in June 2011.

Evaluate child with disability to see if more services are needed - not just give everyone the same evaluation of needs of family to base services on

Everything is fine w/me

Everything is fine with me.

Extend age past 18

family support is a God gift to disabled family who is trying to keep family member at home. Thank you so much

Fast processing

Fast processing

focus not only on elementary ages but more opportunities for adults

For them to help more especially families that are like my child and me.

For them to help more, especially families that re like my child/me. We have been going through a lot. Everyday we struggle, but it makes us stronger. Thank you

For them to help more, especially families that re like my child/me. We have been going through a lot. Everyday we struggle, but it makes us stronger. Thank you

Funding is an issue. The child that is high functionin with disabilities seem to be at a slight disadvantage somehow.

gatherings or connections to other family of autistic children a chance to participate in Special Olympics

Get focus groups and talk about the various types of services, how to improve, etc

get paid faster

Getting cash subsidy sooner

Give more hours to those people that really need them

Give parents a choice of therapists and information about the cash subsidy as an option.

give people what they really need

Give persons who are bedridden around the clock services

Give the workers more help,I know their work load must be great and they still manage to handle it quickly and with a smile.God bless them

Give us our 20% cut back. Those hours being cut has put a hardship on us financially and mentally. Each situation should have been considered instead of 20% cut across the board.

Giver more information to families about services offered.

Go back to original amount given for diapers was \$1200 per year, now \$600

Have a newsletter/e-mail updates of some regular communication.

Have people with a family member with a disability run the program

have someone else determine the level of care that has the experience out in the real world

He use to get respite care so I could pay someone to sit with him to go to town or church.

Help to get them out in the community to do more things

Help with rent/utilities

Higher more staff do to paperwork for me

I am not able to answer. I don't know.

I am not sure at this time because medicaid is cutting so much of our support that it has become a problem with thrying to care for our child. This seems to be unfair.

I feel that to get a good support person they need to be paid more than \$6/hr

I have a hard time knowing the steps for making some things happen, like getting respite care, outside of the family support contract we signed on May 2010. The steps for getting the money received were very clear.

I need more information about what services are available

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I need more information about what services are available.

I really need to know more about any services he can receive

I think it is the best it is going to be considering how many people they help.

I thnik more information about services could be explained or provided

I waasn;t informed by anyone when he was an infant,therefore he was overlooked on waiver program,he just got on a few years ago

I wish it did not take so long to receive the checks

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I would help the people get the hours they need (try raising a kid that is handicap by yourself, and all most lose your job, its hard!!

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I would help the people get the hours they need to try to raise a kid that is handicapp by yourself. It is hard.

I would see or change when you need some others supports with people with disabilities.

I wouldn't change anything besides have more offices open in each parish.

I wouldn't change it.

If a person in home is out of work, let him or her attend to disabled person. Family related. Let someone in the home be the care provider

If I could be more informed of what services are available to us. I found out by accident that we could be supplied diapers after paying out of pocket for a long time

I'm grateful for the help they are giving me.

increase hours per week and for payments to be on time, they lose the paper work sometimes and skip payments

Increase caregivers pay, make funds available for medical equipment

Increase funding - apply for grants, fundraisers, walks, marathon

Increase the amount of hours available, the hourly rate paid to caregivers and decrease paperwork.

Inform case workers more of any additional help that is available to them

inform family about services available

Inform persons about other programs earlier in the process

Intake - we applied when my son was 2 and he was denied. He later qualified at 6. We asked that he be put on the waiver list for when he originally applied - request denied.

Introduce services when persons are younger to benefit

it has been very helpful

It takes too long to get the services that are needed, probably more help and more money to run these programs

It would be easier if invoices could be submitted online. Program should be made know to more people.

It would help if the program didn't have such a long time to get services. Rules for different situations.

Just give a few more hours to it

Just need more hours.

Keep improving the program, so we can keep our loved ones home, safe, healthy and happy

like to receive free camp, free entertainment if available

list to the person that has the disability

Lobby for more financial assistance (keep from services being cut)

Main care giver should receive benefits and not have to hire someone else, offer more services and be more flexible

Make all other services known. I am unaware of listed services above that are available to me.

make all other services known; unaware of listed services above available to me. (what we qualify for and how to get them)

make invoice process easier by just paying the alotted amount and have caregiver verify

Make sure all services are in place before placement is made.

Make the this to wait less.

meet more individual needs

More accessible by phone. Faster processing into program

More accessible by phone. Faster processing into program.

More awareness for all individuals in my situation. Would like to have cash subsidy back because I also have PCA.

More flexibility

More funding

More funding

More funds

More help (funds) so I could better myself (to help my child).

More help and funding

More hours

More hours

More hours

More hours and more areas of help for the children therapies, not paid by insurance.

more hours of service needed to support family duirng weekend hours. More activities for disabled person

more in home care-he receives no assistance on the weekend except for family help

More info available to families

more information regarding services offered

more informations hould be provided to family about what's available

More laws for David.

More money to the program so they could help with more hours

More network information

more NOW hours

more respite hours

More staff to talk to

n/a

n/a

Need communication devices

Need monthly contact

Need more adult day programs, my son wants to have something to do during the day. More activties.

need more hourly help 20 hours a week not enough

need more trained people to help

Need overnight respite

Needs continued services and support. Would like to receive sitter services, household expenses help.

Needs to be more correspondence with families

needs to look at population shift and give the parish the appropriate funds for that amt of people

Nothing. (Appeared 116 times)

OCDD has been wonderful to our family

Offer lists of programs that are available to families. Try/coordinate the individual with programs that offer help

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Offer lists of programs that are available to families. Try to coordinate the individual with programs that offer help.

Offer more income for the PCA.

Only concern is that the check for the person who provides services doesn't go to the person's pesonal bank account (direct deposit). I don't like having the check in my name to have to sign over to this person. Alsos, the length of time between pay/submitting papework is too lonng.

Pay more! We receive \$300 for 120 hours - that is \$2 per hour

Pay the sitter directly

pay the workers more

Payment - it's once a month, shouldn't take 2-3 weeks to get payments if in the office on the 5th

Programs provided need to be implemented in a more timely manner.

Put the sitter's money straight in her account, have to pick up check, cashit, then give them their money

Receive more services

reduce the paperwork that is required by the sitter every month. It is too detailed.

Reimbursement is sometimes slow and with finances so tight it often leaves us financially strapped and stressed.

Reinstate help with utilities

Return more phone calls, explain to individuals what they qualify for

Revamp how the progam is run.

send the individual what is suppose to be sent through the representative and have them give it to the individual

Shorten the waiting list

Shorten the waiting lists for vouchers, etc.

Shorten waiting list

Should be determined on a case by case basis with room to change according to needs of family

Speed up process of waiting list

Stop telling family that they are able to receive more because it is not true. We need a day program in East N.O. for our family and who care to work with our family.

Supplemental money was not enough to cover the times needed to meet our family needs. Such that we placed our child in a community home in Januray, 2011

Take away waiting list to receive waiver benefits

Take politicians out of equation, refocus on disabled citizens and their families

Take time to explain the whole program about assistance with cash montly subsidy.

that it wouldn't take so long to get it started

The amount of paperwork and nonsensical yearly plans that are repetative and fail to grasp the issue. Recent cuts are producing turmoil but the long term effects will tell as the older clients get left out of the system.

the amount of payment needs to be more

The only concern I have is that the check for the person who provides my child services doesn't go to this person's personal bank account (direct deposit). I don't' like having the check in my name to have to sign over to this person. Also the length of time between pay and submitting paperwork is too long.

The people who run Metropolitan Human Services are not understanding and I feel timely with their paper work and rude when trying to communicate with them

the process from changing early steps is not a smooth transition, turned in paerwork for cash subsify in 2007, never turned in, was just placed on waiting list in 2010

The supplemental money was just not enough to cover the times needed to meet our families needs and child's needs...such that we placed our child in a community home in January 2011.

There are so many middle men. I mail in receipts every month for our loved ones expenses. Seems like this could be handled better.

there should be more money given form the state for the program

They are doing a wonderful job.

they should listen to the person responsible and can provide proff from receipts what is needed based on the past and allow that much

To be more receptive to the individual's needs

To help the people who really need it. We were cut hours, I can't work. I need someone for me to work but I can't get any help

To maintain independent living - if there were a facility for persons to be monitored more- but also to let the recipient live in her own individual environment. Similar to assisted living homes.

too much paperwork

Train people who specialize in autistic children

Try to meet family needs as much as possible

Unsure

Wait list is too long

Waiting list is too long. Been on it since 2003 - records lost because of Katrina

We are satisfied with the help this program provides. They answer questions, provide work and socialization for our family member enrolled in the program.

We have been trying to get help for 1 year, and have not yet received any. My mom helps me every day and can't work because of it. I have no money for transportation to help with gas

we wish more services could be provided for us to have night sitter coverage

Wish we would qualify for more services.

Would like more hours

Would need sitter services and household expences would help.

Would rather have a cash subsidy to do/pay for help/services we need

Would rather have just a cash subsidy to do/pay for help/services we need. Too much time in coordinating help of sitters. Not flexible. Would rather just have the money to pay whoever can help the day I need them. Also it pays for help with one child. But it is too restricted in that I can't pay the sitter extra for my other children so I can run errands, etc.

would try to give more hours to the families that don't have much quality time to themselves other than just work hours