

Are There Really "Natural Supports" for Individuals with Disabilities?




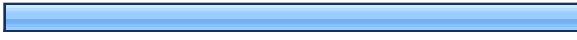


1. I am a

		Response Percent	Response Count
Parent/guardian and caregiver of an individual(s) with a disability		76.0%	73
Parent/guardian of an individual(s) with a disability		16.7%	16
Caregiver of an individual(s) with a disability		5.2%	5
Individual with a Disability		2.1%	2
answered question			96
skipped question			0








2. The individual with a disability is the following age

		Response Percent	Response Count
0-4		4.2%	4
5-9		9.4%	9
10-14		10.4%	10
15-19		18.8%	18
19-24		21.9%	21
25+		35.4%	34
answered question			96
skipped question			0




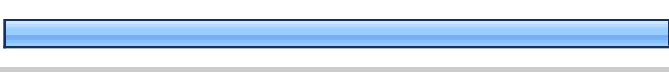

3. Choose all that apply. The individual with a disability has a

		Response Percent	Response Count
Physical disability		53.1%	51
Cognitive disability		86.5%	83
Mental Health Disability		39.6%	38
Other (please specify)		22.9%	22
		answered question	96
		skipped question	0





4. Choose all that apply: I have "natural supports" that I can regularly depend on to help from the following:

		Response Percent	Response Count
Immediate extended family (brothers, sisters, grandma, etc.)		17.7%	17
Neighbors		3.1%	3
Friends		8.3%	8
Church		5.2%	5
Social group		1.0%	1
None that I can think of		60.4%	58
Other (please specify)		24.0%	23
		answered question	96
		skipped question	0

5. I feel that my level of help and support from my "natural supports" is

		Response Percent	Response Count
Strong		0.0%	0
Moderate		0.0%	0
Little		0.0%	0
Miniscule		100.0%	96
No support from "Natural supports"		0.0%	0
answered question			96
skipped question			0

6. I have been made to feel "guilty" by other parents, professionals, service folks, articles in magazines/bulletins, the "system," and/or others regarding my level of having "natural supports"

		Response Percent	Response Count
Never		30.2%	29
Sometimes		32.3%	31
Frequently		26.0%	25
A lot		11.5%	11
answered question			96
skipped question			0

7. In regards to training in gaining and using "natural supports"

		Response Percent	Response Count
I have received no such training		68.8%	66
I have received training and it has not been helpful		21.9%	21
I have received training and it has been somewhat helpful		8.3%	8
I have received training and it has been very helpful		1.0%	1
		answered question	96
		skipped question	0

8. Please provide comments and thoughts about any aspect of "natural supports" you would like to share. This is an anonymous poll.

	Response Count
	75
answered question	75
skipped question	21

Q3. Choose all that apply. The individual with a disability has a

1	Neurological	Apr 13, 2011 8:27 PM
2	non-verbal	Apr 13, 2011 10:56 PM
3	intractable epilepsy and autism	Apr 14, 2011 7:46 AM
4	Behaviors with Agression, due to sever Autism	Apr 14, 2011 10:26 AM
5	DS/ASD	Apr 14, 2011 11:30 AM
6	PDD Autism w/ explosive episode disorder	Apr 14, 2011 11:58 AM
7	Hearing impaired	Apr 14, 2011 3:58 PM
8	seizures	Apr 14, 2011 6:17 PM
9	I have Pick's and am losing my mind	Apr 14, 2011 8:43 PM
10	diagnosis of Down syndrome	Apr 15, 2011 8:46 AM
11	autism, among other issues	Apr 16, 2011 12:49 PM
12	Brain injury	Apr 16, 2011 6:37 PM
13	autism	Apr 18, 2011 7:45 AM
14	Mood, severe ADHD, speech/language deficits	Apr 18, 2011 9:24 AM
15	Medical Disabilities including heart defect and sleep apnea which cannot be treated.	Apr 18, 2011 10:45 AM
16	Autism Spectrum Disorder -low functioning/MR/Epilepsy	Apr 18, 2011 1:30 PM
17	Visual Impairment, Epilepsy	Apr 19, 2011 4:08 AM
18	Aspergers Disorder	Apr 19, 2011 10:28 AM
19	speech/communication	Apr 21, 2011 12:53 PM
20	Autism	Apr 21, 2011 1:39 PM
21	Autism	Apr 21, 2011 6:32 PM
22	developmental Autism	Apr 25, 2011 10:34 AM

Q4. Choose all that apply:**I have "natural supports" that I can regularly depend on to help from the following:**

1	People offer, but after a while, unless they have personal experience, they drop away. They expect "progress" and don't see any.	Apr 13, 2011 10:51 PM
2	When I say immediate. There is only one person besides myself that can dependably help me care for my child.	Apr 13, 2011 10:56 PM
3	rarely, my sister	Apr 14, 2011 7:46 AM
4	minimal family support	Apr 14, 2011 8:44 AM
5	While there are some more temporary people in his life, there is no one who I can depend on regularly. Not even family.	Apr 14, 2011 9:08 AM
6	My immediate Family consists of myself a 49 year old, 5'2', single mom; my 20 year old son that is busy with school and his social life; and my 54 year old sister. Both my parents are dead. My exhusband, the father of my children is long gone and I don't even know where he lives, somewhere maybe in California. He stopped sending child support at least 5 years ago, and before that it was irregular. He stopped taking his son for an occasional visit on a weekend at least 7 years ago when his girlfriend refused to allow my son in her home stating that he was uncontrollable like an animal.	Apr 14, 2011 10:26 AM
7	We have a couple of people who I feel we could call but on an ongoing basis I would have to say we DO NOT have "natural supports."	Apr 14, 2011 5:09 PM
8	People I pay to support me.	Apr 14, 2011 8:03 PM
9	I live alone so I really don't have anyone to become a caregiver	Apr 14, 2011 8:43 PM
10	Occasional financial help with medical bills from my sister. Otherwise, I don't know what "natural supports" means. But I don't have any family, neighbors, or friends etc. that can help us out on regular basis.	Apr 15, 2011 8:46 AM
11	I have friends, but most have their own kids with disabilities and it would be wrong to impose on them.	Apr 17, 2011 11:19 PM
12	I only have one daughter in town who can help me in an acute emergency, but I cannot rely on her for much support due to her own schedule (student).	Apr 18, 2011 9:24 AM
13	I have one person I can call only if it's an extreme emergency; I have one neighbor that will get him off the bus if she is home, until the Direct support worker can get there if she's tied up and is a few minutes late for the bus. My husband and I are only other supports for our son.	Apr 18, 2011 10:45 AM
14	natural supports would be me, my child's mother. However, I am single, work more than full time as a professor and have no family/friends local that can support. Severity of daughter's problems do not lend themselves to natural support help. My daughter's father lives 5 miles away and works.	Apr 18, 2011 1:30 PM
15	A few now and then but not regularly available to fill in when his occasional staff is not available.	Apr 18, 2011 2:18 PM
16	for socializing but not for caregiving	Apr 18, 2011 4:58 PM

Q4. Choose all that apply:**I have "natural supports" that I can regularly depend on to help from the following:**

17	Occasionally if there is a funeral or wedding my friend will help out otherwise its up to our immediate family to provide continual care.	Apr 19, 2011 6:37 AM
18	I have 2 people who will help, not regularly, and they are in their seventies.	Apr 19, 2011 9:02 AM
19	Other parent of child with disability Occ with school employees	Apr 19, 2011 11:24 PM
20	very limited. other people help but don't understand all the time needed	Apr 21, 2011 12:45 PM
21	We have a few people that we pay once in a while out of pocket	Apr 21, 2011 12:53 PM
22	only receive sporadic support, not regularly dependable or desirable.	Apr 21, 2011 2:01 PM
23	Paid sitters	Apr 21, 2011 6:32 PM

Q8. Please provide comments and thoughts about any aspect of "natural supports" you would like to share. This is an anonymous poll.

1	We are the natural supports and the necessity is lifelong. There are more and more needs with the the degree and complexity of an individuals disability. Most people that push natural supports have never walked in our shoes, and yes it is the easy answer to budget issues. One of the worst parts is that we have to keep educating the world that this doesn't just last a week, month, or years but a lifetime and it gets even more difficult when a person reaches 21.	Apr 13, 2011 8:27 PM
2	We have no extended family. The only natural support for our daughter is her brother, who lives out-of-state and can assist only very occasionally. Aside from that, our daughter's physical needs are so intensive that there are no friends, social groups, churches, volunteers, etc. who are both willing and competent to take them on. All the people who provide care for our daughter, with the exception of us (the parents), are paid. I have heard many parents of children with DD express how disappointed they are that everyone in their child's life is paid to be there.	Apr 13, 2011 8:38 PM
3	I am a part-time caregiver for my adult son with severe physical disabilities and a full time caregiver for my husband who became a hemiplegic and intellectually disabled after a severe stroke. Prior to his illness, we had many friends here in Denver and family that called despite being out-of-town. When he had the stroke, many people expressed concern and helped, but that was four years ago and now we literally NEVER have people come and visit him, take him out to Starbucks (he drools and constantly coughs so not socially acceptable) or whatever. I also have a full time job, which I now do at home, but I am so overwhelmed. My health is failing and I can no longer sleep well for worrying. Natural supports are what you have when it is easy to support you. Once it's hard, the truth is that it's natural to resume you own busy life and better to be occasionally guilty than take on something that's esthetically, physically, and emotionally difficult. I do understand that it's hard to support someone longterm. Some folks may have endless "natural supports," but my experience is that people can not sustain extraordinary, unending assistance.	Apr 13, 2011 9:26 PM

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4	Natural supports is another term for free help. Not many people with time nor the talent to help with my child.	Apr 13, 2011 9:29 PM
5	When it comes to people who have very complex disabling conditions where "progress" is minimal or absent, "natural supports" burn out. When your family, friends, co-workers... tire of hearing about what is needed, it is very hard.	Apr 13, 2011 10:51 PM
6	In my case people are too afraid to watch my daughter as they cannot take care of her 24/7 needs and are just afraid of being responsible for her, and it's not as simple as watching a cute child who can take a nap and eat whatever she wants and you can do whatever you need to with your day. She doesn't walk well, doesn't talk, her blood sugars have to be monitored, her free water intake has to be monitored every bowel movement/urine output must be monitored, amounts of food and eye ointments, and therapies (3x a week.) And it takes a lot of understanding medication and what to look for and how to deal with it. She is non-verbal, diabetic. The only person willing to help me was my mother in law. And even she cannot watch my daughter over night or past 8 pm as there are medications that have to be given and she draws the line at being responsible for this set of medications. I am military and sometimes am required to work shift work with little notice. And it becomes a challenge if my mother in law cannot watch my daughter. I have no one else. It's not that they don't want to help. They just don't feel capable enough to help. It's medication, food types, sign language, responses, schedules, logs. And they just can't keep up with it. I am very blessed to have someone who is willing to try to learn even if they get it wrong, they bounce back instead of giving up. But I know many many people have to quit work to care for their children because no one can take on the full time responsibility. If I didn't need the income to afford for my other children, I would have to stay at home with her. Even though she is self moving and able to feed herself. The amount of 'other care' that is needed goes beyond what a daycare would be able to handle but doesn't qualify for in home nursing care programs. And I can't afford a medically trained Nanny.	Apr 13, 2011 10:56 PM
7	while family and neighbors and friends have provided support in many ways it never involves directly caring for my son. My sister used to but ever since he pulled her hair she has stopped and makes me feel guilty for asking	Apr 14, 2011 7:46 AM
8	Natural supports are great when available. They must be nurtured, and as the sole caregiver I do not have time to nurture these relationships. My teen-age son has outgrown the cute stage. We live in a small mountain community. People in the community will rally with support in times of great need (like if I had to go to the hospital), but on a day to day basis I am on my own. For example, I can hardly even get outside for exercise because I am afraid to leave my son alone in the house. There have been times when I have gone outside to fill the birdfeeders, which are right next to the house, and walked back inside to a 'disaster.' Now that he is eligible for adult services he is on a waiting list for agency supports that are only provided in a community 45 minutes away. Yikes. The church has been of no support, the child's mom left because she was bored with his disability, my parents are aged and have their own needs for support. I am tired, but still here.	Apr 14, 2011 8:26 AM
9	sucks when you are seeking services from an agency and they tell you to use your family.	Apr 14, 2011 8:44 AM

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10	I believe the system is kidding itself if it thinks that we could actually find people who would have this kind of commitment to adult children. The world is too busy. People have to work. It is a lot to ask people to help. At "best" we "might" be able to get people to be there in an emergency situation only. Natural supports are a farce.	Apr 14, 2011 9:08 AM
11	My son has severe Autism with severe behavior issues. He also takes a lot of medications. He is non verbal and very aggressive. When he was only 6 years old, I asked my neighbor to watch him for a short while. My sister, who also has no one else, had fallen and needed to go to the hospital emergency room. When I returned home after about 3 hours, my neighbor was fine but said that she was in awe of my strength and courage and how hard it was to take care of my child. She said she wasn't comfortable and she was sorry, but she couldn't watch him again, ever. Another time, before I started working at Bright Horizon, the Broward Center School for children with disabilities, were I now hire my respite workers because I am on CDC+, I had been given an agency that would give me a few hours a week, The girl they sent had not been trained at all, and it was her first job. Realizing this I was uncomfortable leaving my son with her, but I really need to go up to the grocery store, I was gone no more than 45 minutes. When I got home the girl was on my front porch with her car keys in her hand, and ran to her car the moment I pulled up. I went inside to find my son in a soaked diaper with a 2liter bottle of Coke. Later when I called the girl, she said that my son tried to hit her in the head when she went near his diaper, and he took the soda from the refrigerator so she let him. She also said she wasn't coming back, like a would ever ask her again. Another bad experience with another agency was when another new worker called the police because my son bite her while she was trying to get him on the bus. My son, due to his disability, doesn't understand social interaction, he is tall and heavy, much larger than me, and he has no understanding of his strength or hurting someone. I can not ask anyone to watch him, he is 16 1/2 year old, wears diapers, has trouble with bowl movements, so they usually are soft and go up his back requiring a shower, he can get aggressive, even if someone has good intentions the can not handle my child, again , due to his type of disability.	Apr 14, 2011 10:26 AM
12	Family members are non-supportive. I tried the church and recvd the "just pray" support which didn't help my child or myself. Friends have their own lives and are not available to assist.	Apr 14, 2011 11:06 AM
13	1. Family is widely disbursed. 2. Community is 'friendly' but doesn't offer support. 3. We are old and tired and to search for people willing to 'offer' requires us to 'ask'.	Apr 14, 2011 11:30 AM
14	Since few of us live in rural communities and extended families are usually spread across state lines, it is difficult to find natural supports. Also as our children age so do we, and one day we will be gone. Then what supports will they have. FL provides very little help with any kind of decent services for the disabled, so parents are usually the only support.	Apr 14, 2011 11:58 AM
15	Natural Supports is great for those who have that available, but in our case we don't. Plus my son has behavioral issues in addition to his cognitive deficits which makes him difficult to watch. His brother no longer will watch him because of his behaviors.	Apr 14, 2011 3:58 PM

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16	Natural supports is a great idea - except either there is no family available, neighbors don't want to take on that responsibility, all responsible adults work, siblings are not old enough to take on the responsibility, etc, etc, etc. I'm it!! And I'm only it because of the state payments I receive to maintain the home the person with disabilities lives in and has lived in for 10 years.	Apr 14, 2011 4:41 PM
17	When you have a child with an ongoing chronic disability it seems to much for others to handle and they bail. I would LOVE to have natural supports but my energies are taken up taking care of myself and my children. It is very hard to forge friendships when they KNOW you are going to need their help. This is a real friendship killer. In the past, the "natural supports" I had seemed to think they KNEW how to make myself or my children better or gave words of advice where they were ignorant of the actual issues surrounding our disabilities. I have yet to find a someone who is in it for the long haul and can support me without tearing me down.	Apr 14, 2011 5:09 PM
18	very hard to find people willing to help with little pay	Apr 14, 2011 6:17 PM
19	I have no other family members to help out. Community members and neighbors may offer help, but it usually is not when and how I need help. Many times, I have found when I do try to use a community member to help it turns into more work for me----for example, I have to provide the transportation for my adult child to someplace I would not normally go to; this takes my time and money for gas. For example, there are groups that offer dances or other social activities for people with disabilities, but again, I have to provide the transportation and then I wait in the car until it is over. Often the times of these kind of activities conflict with my other commitments, so my adult child can't participate in them.	Apr 14, 2011 7:05 PM
20	I feel isolated and ostracized a great deal of the time. I have a very small group of ppl whom I would consider "natural supports." There is a larger group who say they would like to support my family and I but are reluctant to step up. When asked to assist/support most often have a myriad of reasons why they can't. This happens often enough so I have, pretty much, stopped asking at all. If I can't buy the support, I don't have the support. Continuous and constant rejection are no longer my cuppa tea.	Apr 14, 2011 8:03 PM
21	for me before I reach the point I will need help I have made my plans terminate so I won't need a caregiver	Apr 14, 2011 8:43 PM
22	Close friends and family do come through in a pinch but there are no regular natural supports in our life for our son.	Apr 14, 2011 11:34 PM
23	Everyone is too busy with work and maintaining their own health and families to offer us anything more than moral support! I have TWO DD young adults living at home. No family or friends EVER offer to provide respite!	Apr 15, 2011 7:29 AM
24	What does natural supports even mean? We have no disposable income. We do pay for health insurance and we take advantage of it all the time, but it does not provide for therapeutic benefits like PT, OT, and speech therapy.	Apr 15, 2011 8:46 AM

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25	My husband and I live about 40 miles from family. Of the family, only my adult nephews are physically able to care for my son. He is a runner and needs assistance to toilet, feed himself, etc. When he lived with us (until 6 months ago) and we had an event where they live, we have taken my son to them for a a 2-4 hour visit. Other than that it was easiest to hire capable, willing people to spend time with him near home. Our son always does best with routine and familiar surroundings--I think it makes him feel safe, he knows what to expect. He doesn't crave variety.	Apr 16, 2011 5:52 AM
26	Our son has a very rare chromosome disorder with a lot of mental health issues. Physically he looks normal. It is very difficult to get immediate family, friends, or anyone who is not around him everyday to understand the full scope and complexity of his disability. The people who do fully understand are very hesitant to help because of the difficulty and stress, and others view him as a normal child who has issues due to poor parenting.	Apr 16, 2011 6:13 AM
27	We have family and friends in the area and we belong to a church group. So we have many people who could qualify as "natural supports." But the reality is that family does not feel comfortable with our kids, church people do not know our kids well enough to be comfortable with them, and friends would help but have other responsibilities of their own.	Apr 16, 2011 12:49 PM
28	I have natural supports that can be counted on for short periods of time in case of an emergency. None of my natural supports could be counted on to provide regular, ongoing, volunteer support. My son's needs are too extensive to ask someone not related to him to undertake.	Apr 16, 2011 3:12 PM
29	Natural support is a great idea if it is available. I support individuals from the institutions in KY. The community does not accept them as their own and they do have struggles while transitioning! Most of them do not even have family that want to be involved!	Apr 16, 2011 6:37 PM
30	Natural supports seem to be more available when your children are young. As they age their disabilities become more complex. Friends and family members may not be equipped mentally and physically to deal with these complexities. As parents and guardians age their needs may become such that they need help and support. Siblings go on to have their own families or move away and are not always available to provide care. Parents have enough stress to deal with, without having to recruit and train others. What happens when the parents die? Who gets stuck with the responsibilities then?????	Apr 17, 2011 3:32 PM
31	I only answered number 6 with "never" because I refuse to let anyone make me feel guilty about my family situation. Reality is, though, I will not be able to keep up this level of care forever. It is exhausting, both mentally and physically. Unfortunately, I have no doubt that my son will receive very few services because he IS cute and chatty with other adults. He is only difficult if you ask him to do anything. Of course, life requires us to do things. The basics, like eating, staying dry at night, understanding money, laundry, transportation, and cooking are a constant difficulty. Even if my family lived close, they couldn't handle his anxiety and frustrations, plus his constant needs would overwhelm him. As for church, they don't get it. They think if they don't kick him out of the youth group they are helping. They don't realize that he won't stay if he is not included with respect because it won't be fun. It becomes just another place that he feels unwanted. Plus, they always want me to volunteer because they don't know how to handle him. I never get a break away from him. So much for natural supports.	Apr 17, 2011 11:19 PM

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32	Natural Support. That is a joke, right? What support?	Apr 18, 2011 6:41 AM
33	Most of those that would be considered "natural supports" are not willing to care for my son because of his complex medical needs.	Apr 18, 2011 6:52 AM
34	I haven't sought training on "natural supports". My family just isn't an option. Paternal grandparents are dead, even the child's father isn't the most helpful. For some families, there is just no such thing as having natural supports.	Apr 18, 2011 7:10 AM
35	Just because someone has family members that they spend time with doesn't mean they will help. I know people who have family members that are not willing to help and some their family members are older and the are not able to help. And as I said some just won't help, they don't want to help or be bothered by what it takes to take care of someone with a disability. Just because they are your natural family doesn't mean they are compassionate, caring or giving. It may seem odd to those that have a wonderful natural support system but in some family's their own family is just as prejudice and uncaring as the rest of the world who really don't care about people with disabilities or who are embarrassed by them.	Apr 18, 2011 7:55 AM
36	I believe that it should begin at the developmental disability start of pre-k and evolve with the individual child. This would allow the parents to grow with the system and instruct them on using these supports.	Apr 18, 2011 8:44 AM
37	Three of my son's grandparents are deceased - and obviously not a support. The remaining Grandmother is 85 and unable to care for a person with a profound physical disability. My son's brother and sister are away at college and cannot help. His Aunts and Uncles all work full time and have families of their own to care for. Most importantly, my son with a disability has profound quadriplegia and our family and friends are "afraid" to take care of him for fear that they will "hurt themselves. I am not being pessimistic when I say - we have no "natural supports" Quadriplegia is not "natural"!	Apr 18, 2011 8:50 AM
38	I have almost no family in the area and of those that are here, only two could help IF there was an acute emergency. They are either working full time or are students. It's very frightening to know how little I have in natural supports in case of an emergency where I couldn't care for my daughter with special needs.	Apr 18, 2011 9:24 AM
39	While my mother was alive (she died 5 years ago) we had a WONDERFUL natural support in her. She had a close and loving relationship with our daughter, now 22, who has severe autism, and spent time with her minimum twice a week, doing favored activities that both enjoyed. She was a huge help to our family. Her death was a huge loss for many reasons, and we miss her dearly.	Apr 18, 2011 10:23 AM
40	I have family but I feel they are not capable of caring for my little girl. It is very hard to navigate the world of caregivers to find someone appropriate to help with her when we need it.	Apr 18, 2011 10:40 AM

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41	You spend so much time dealing with schools, doctors, therapists, and on and on, there's not much time for your socialization so how do you build relationships that lead to natural supports?! The relationships I've formed are with others in my same boat because we cross all the same paths. My friends all have at least one child with a severe disability and three friends have 2 children with severe disabilities. They are looking for support themselves. My sister lives too far; my parents are too elderly. Relying on natural supports is fine if you have them. But if you don't, there has to be help. It's too overwhelming.	Apr 18, 2011 10:45 AM
42	Natural supports don't do any good if they are a thousand miles away! All of our family lives out of state, therefore, there is actually no natural support to help us! Besides, is it not the school system's responsibility to help us educate our son?	Apr 18, 2011 11:07 AM
43	I have nothing constructive to say. My mother taught me that if I have nothing good to say, I shouldn't say anything.	Apr 18, 2011 12:59 PM
44	My daughter's disabilities are such that I am not comfortable with natural supports caring for her. My child needs a personal care attendant when I am not available to care for her. My job supports us though and that must be prioritized. Therefore, my child needs a personal care attendant.	Apr 18, 2011 1:30 PM
45	Most natural supports run like hell when they see you coming, avoid the phone when your on the other end, or pretend not to hear the door when you knock. Our child is a handful to say the least, they wear us out in no time at all and we are suppose to be 'used' to it. What do you think the parent who is not accustomed to it feels like? In thirty minutes they are watching the clock tick by and biting what is left of their nails off, waiting for you to get back. Paid respite is hard to find, free respite is almost unheard of. It takes a very special family member, or other 'natural support' to be there and be there often. It's a hard job, we try not to complain often, but when you cut an already short budget it makes one angry!	Apr 18, 2011 1:46 PM
46	Because he has behavioral issues, it is difficult to find others who are willing to assist. He seldom has consistent staffing.	Apr 18, 2011 2:18 PM
47	Family too busy	Apr 18, 2011 3:02 PM
48	Our family is very small and lives all over the US so there is no "natural support" from that. Our church loves us but no one there has the training to deal with our son and his disabilities. Natural supports is a ridiculous term that people in the system have created to try to blame parents and families.	Apr 18, 2011 4:58 PM
49	I provide care for a young lady with MR and Bipolar Disorder. She has a very hard time making and keeping friends due to her disability. She was doing better with behavior and mental health services but her services have been cut in half. She is now in teir 4 and has lost her dental and mental health. She has to decide between having a companion and getting behavior services. She has a little of both but it is not enough. I feel sad for her because she has so much potential. Her mother was a drug user and that probably caused her disability. This young lady has been let down her entire life. She has no family or real friends and depends on paid supports.	Apr 19, 2011 1:15 AM

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50	I think it is asinine to think that the disability services system which has never been fully funded will be there to fund every one of us. I think it is our parent duty to support our children, but that doesn't mean that there shouldn't be some support from the system as well. We all need a healthy balance in our lives of paid and unpaid supports. This shouldn't be any different for my daughter who has significant support needs. In our state, there is no equity - she gets no services, beyond special education, that support her or our family the other 158 hours of the week while lots of families get an overabundance of funding and services. We "make too much" to qualify for SSI. She can "sit on a waiting list" for decades for Medicaid Waivers, but why bother when the services are pre-defined and not what she might need. Why this reliance by everyone on Medicaid?!	Apr 19, 2011 4:08 AM
51	Nonverbal, behavior issues, make it very difficult to find willing unpaid supports.	Apr 19, 2011 4:51 AM
52	When our child with a disability was young Grandparents may assist if asked but only if we asked and only if it was an emergency. Very gratefully, my Mother did one weekend a year came over 2 nights so we could go away for a long weekend away and that was so appreciated. My two sister in laws and niece helped when they could but they had children to care for and they work so their time was limited but in emergencies they were there. Now my adult child has no Grandmom, my sister in laws are not able to help and unless my 40 year old son can assist we have no natural support - he has a family and we only ask him in emergency situations. We hear people retirement can go on extended vacations or even out for a day and just get in the car and go with no plans or destination in mind - we would pray for the day that we could enjoy a peaceful time away together for a brief respite so that we can come back strong to continue to care for our adult child who we love dearly.	Apr 19, 2011 6:37 AM
53	They would be great if they were there. Sometimes, it just isn't possible because there are no natural supports.	Apr 19, 2011 7:00 AM
54	I think most people think it is as easy as 1-2-3...just going out, meeting people, & BAM! There is your social network. If you are not in the life of raising a child w/ a disability, then one will never know how utterly difficult it can be to connect with others. The truth is that some people, yes, even family, do not want anything to do with you, or it might not be healthy to be around their negativity. Any way you look at it, "natural supports" is not the answer, nor will it ever be.	Apr 19, 2011 7:41 AM
55	With certain disabilities it is overwhelming to a "natural support" person to look at all of the possible issues and be prepared. The idea that all persons with disabilities will be "easy" enough to be supported by free help is just another attempt at cookie cutter approach to dealing with persons with disabilities.	Apr 19, 2011 9:02 AM
56	My son is too severe for someone to want to care for. If there is an absolute emergency, I might be able to get someone to watch him for an hour. No one wants to get beat up or chase a child down the road for even what respite workers and behavioral assistants are paid. I have offered to pay friends and they still say no way	Apr 19, 2011 9:37 AM

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57	Each situation is different--one size does not fit all. As a parent, I respect those who can/are willing to provide 24 hr. care for their family member; however, I also respect those who are unable to do the same, for various reasons. I also think it's unfair for people/parents/professionals to judge others and force their opinion on everyone, just because they either are able themselves to depend on natural supports and are successful at providing 24 hr. care or they expect natural supports to do so. I believe the underlying motive (not of parents) of this belief is for funding reasons only. I think the best for many individuals is to be cared for by their family; however, I don't see that as a true option for many families. My real focus is to improve the direct care staff that provide care for people with disabilities. It seems like the low pay attracts the most undesirable people to apply for this work. Our most vulnerable people in our society, people with disabilities, those who are elderly, and our young children, deserve better quality care than most are receiving.	Apr 19, 2011 10:06 AM
58	We are living in rough economic times. Outside of my immediate family, which includes 2 disabled adults, and 3 special needs children, I have one friend (who has one special needs child), who can occasionally offer a helping hand. I spend the majority of my day advocating for a free appropriate public education for my 3 school aged children. I try to spread out my time to be available for each child. I do find many teachable moments. I get very little sleep at night due to the latter. I have a college degree. Natural supports, for most families, is negligible.	Apr 19, 2011 10:28 AM
59	Natural supports to me are ME.. As an older parent of a 22 yr old aging out of school...there is NOTHING out there... Yes Special Olympics, community activities are great but what about employment, job coach, daily living coach (before I die), quality transportation, therapists & someone to help coordinate it all ?	Apr 19, 2011 3:11 PM
60	Sounds great in theory, but reality is much more difficult to find these "natural supports". This has been true for our entire journey so far.	Apr 19, 2011 11:24 PM
61	The only natural reliable support that my daughter has is me. She has four brothers, three of whom live in the same town as she and I do. Her four brothers have wives, children, school, church, work, and community obligations and are not available to "help" me with my daughter's care. I have provided her care prior to the waiver, during the waiver, and often even now that I am over the magic age of 70. When a paid caregiver does not show up to care for my daughter, her care falls on me. I recently has major surgery and still there is no continuity to her care. I wonder what happens when I die?	Apr 21, 2011 9:42 AM
62	sometimes if you have an individual who is independent, people think you don't need support. but you need support the same as others.	Apr 21, 2011 12:45 PM

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63	<p>Natural supports would be great, but they can not carry the responsibility, reliability and commitment that is needed to meet our son's unique needs. The person supporting him needs a level of expertise and must take care of his personal care needs, this is not something that we can push onto others that he is trying to have a typical relationship with. He needs supports to have relationships, not relationships based on him being the receiver of supports, that is devaluating and demoralizing. He's been fully included throughout his education and went to his proms with peers, but had an aide to support him, it would not be appropriate to change his personal friendships to watching him like a baby-sitter, or to take him to the bathroom or be responsible to feed him and assist him so he doesn't choke. This was brought this up at his ISP for when we hope he moves onto supported employment, but it would change the quality of his life. It would reduce and limit the skills and accountability of the people needed to support him, "if" we could find people in the first place. We don't have anyone who will spend time supporting him unless they are paid.</p>	Apr 21, 2011 12:53 PM
64	<p>Autism requires training and building a relationship;it is different than anything else out there : the lack of dynamic abilities is dishearting and not easy to understand for most "natural caregivers". Its hard to find respite much less professionals. This is a way of the goverment to rid themselves of the "burden" of taking care of our own. Why then pay taxes if its not for the good of the people? I pay school tax, but have no children in school-should I ask parents to find "natural teachers"? This natural implication is a farce.</p>	Apr 21, 2011 1:39 PM
65	<p>Natural supports is wonderful for the very few who have this in place. My situation is dire. I cannot find and/or keep a job as I have NO ONE to care for my two adopted sons. Their father rarely takes them to give me a weekend break. I often refer to myself as 'handicapped by proxy' as I am stuck with a small window of opportunity to hold a job---a window so small and with so many exclusions (kid is sick, ice/snow, no transportation or workshop due to holiday, etc.) that I am not even considered for the job should I even get to the interview stage. I suffer from hypertension, am pre-diabetic and have depression and anxiety. I also have bad joints and pain from arthritis. I am only 54, sometimes feel like I am 90. I worry about what would happen should I get sick. People in my situation need HELP, The lawmakers need to understant this.</p>	Apr 21, 2011 5:04 PM
66	<p>Natural supports are great but my husband & I are the youngest children of older parents & are now providing care for them. We get occasional help to go to weddings/funerals but any not daily/weekly help. We turn down invitations alot because we don't have the support to get out. I envy people who go out to dinner & movies because that is like luxury that we can't do. It is true that the higher the needs of the child/more severe the challenge, the more difficult it is to get help. Especially, if there are any medical needs. Parent caregivers- a truly underserved population.</p>	Apr 21, 2011 5:15 PM
67	<p>I am not sure what natural support can, or are supposed, do to help me and my family</p>	Apr 21, 2011 6:32 PM
68	<p>I moved to Central PA before my son was diagnosed. We have no family and very few friends around who understand my son's autism. Finding help has been a severe challenge.</p>	Apr 21, 2011 6:34 PM

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69	Both my husband and myself work full time. Our son goes to school full time. We thankful for employers who allow us to alter our work hours for before and after school so that we don't have to rely on anyone unless we are held up. We have one close friend who can help if we need and occassionally my father's father...other than that, we don't want to burrdon anyone or ask for help. I have tried to search for child care for summer care, but I usually end up using a responsible teenager to come to our home.	Apr 21, 2011 6:52 PM
70	as we've aged, the supports have dwindled. We need to work more to deal with increased costs of living and the college expenses from other children, vehicle and home costs - and more. We rarely get time for respite an evening out costs for a sitter --- in excess of \$100 commonly since my child weighs over 200 lbs. and can be aggressive. Natural supports? hah hah my parents and inlaws are in their 80's, my other children's educations and jobs took them 100's of miles away, I do not participate in organized religion any longer - the remaining congregants are older; and the disability support groups focus on families with youngsters. My own health is failing. If there is an expectation that natural supports exist that will fill in when funding fails --- it is a fantasy. I know of no instance of people with post high school aged children who have reliable natural supports.	Apr 21, 2011 8:16 PM
71	Natural supports are so limited---limited to a few well meaning relatives without the time to really make any difference regarding real caregiving. Without pay and /or a calling for service work, it's hard to live the 'double life' caregiving requires you to do.	Apr 22, 2011 12:46 AM
72	Family lives far away but is supportive. Friends and neighbors are supportive too but are very busy with own lives.	Apr 22, 2011 7:59 AM
73	I do not use 'natural supports' for my adult child. It has been my experience that such support is none existent or at least very infrequent and haphazard. Friends who have relied on such supports have been deeply disappointed in the support provided.	Apr 22, 2011 2:04 PM
74	Careing for my child in her younger years was so intensive that my husband and I lost contaact with our church, most family, & friends.Our ability to start new relationship was limited to families of other disabled children and the professionals who support them. Currently to support our daughter a caretaker must have specialized training. It is not realistic to use natural supports except on a very limited scale.	Apr 25, 2011 6:59 AM
75	I am a 58 year old single parent of a young man with Autism. There are no natural supports. My immediate family has no training to care for my son. Very little such training is even available. The only training would come from me. Training for non-natural supports is not out there either. It is ridiculous to think that "natural supports" is the answer as opposed to proffesional service providers. Some families simply don't have that kind of network or resources. Some families have aged out, and the parents are beginnig to need supports as well as their child.	Apr 25, 2011 10:34 AM