

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		89.5%	68
Parent/guardian of an individual(s) with a disability		9.2%	7
Caregiver of an individual(s) with a disability		1.3%	1
Individual with a Disability		0.0%	0
answered question			76
skipped question			0

2. The individual with a disability is the following age			
		Response Percent	Response Count
0-4		0.0%	0
5-9		0.0%	0
10-14		100.0%	76
15-19		0.0%	0
19-24		0.0%	0
25+		0.0%	0
answered question			76
skipped question			0

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

		Response Percent	Response Count
Physical disability		47.4%	36
Cognitive disability		81.6%	62
Mental Health Disability		28.9%	22
Other (please specify)		27.6%	21
		answered question	76
		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.)		51.3%	39
Neighbors		9.2%	7
Friends		23.7%	18
Church		18.4%	14
Social group		5.3%	4
None that I can think of		27.6%	21
Other (please specify)		21.1%	16
		answered question	76
		skipped question	0

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

		Response Percent	Response Count
Strong		13.2%	10
Moderate		23.7%	18
Little		27.6%	21
Miniscule		13.2%	10
No support from "Natural supports"		22.4%	17
answered question			76
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		44.7%	34
Sometimes		35.5%	27
Frequently		14.5%	11
A lot		5.3%	4
answered question			76
skipped question			0

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

		Response Percent	Response Count
I have received no such training		75.0%	57
I have received training and it has not been helpful		13.2%	10
I have received training and it has been somewhat helpful		7.9%	6
I have received training and it has been very helpful		3.9%	3
		answered question	76
		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
	41
answered question	41
skipped question	35

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

1	Traumatic Brain Injury	Apr 14, 2011 3:27 PM
2	profound hearing loss	Apr 16, 2011 7:07 AM
3	autism, among other issues	Apr 16, 2011 12:49 PM
4	seizures	Apr 17, 2011 2:14 AM
5	autism	Apr 17, 2011 2:57 PM
6	autism	Apr 18, 2011 8:08 AM
7	Medical Disabilities including heart defect and sleep apnea which cannot be treated.	Apr 18, 2011 10:45 AM
8	Autism Spectrum Disorder (PDD-NOS), Learning Disability	Apr 18, 2011 11:41 AM
9	Autism, Down syndrome, amputee and medically fragile	Apr 18, 2011 2:47 PM
10	Fragile X Syndrome	Apr 18, 2011 6:44 PM
11	autism spectrum and muscular dystrophy	Apr 18, 2011 8:20 PM
12	hearing	Apr 18, 2011 8:47 PM
13	specific learning disability	Apr 18, 2011 9:49 PM
14	Autism	Apr 19, 2011 9:54 AM
15	Autism	Apr 19, 2011 3:27 PM
16	autism	Apr 19, 2011 4:11 PM
17	special health care needs	Apr 19, 2011 9:42 PM
18	Profoundly hearing impaired	Apr 20, 2011 9:40 AM
19	I have two adopted children with severe disabilities	Apr 20, 2011 9:56 AM
20	deve. delay and seizure disorder	Apr 21, 2011 8:01 AM
21	vision, endocrine, more	Apr 21, 2011 9:37 PM

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

1	Friends from child's school	Apr 13, 2011 9:56 PM
2	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
3	People I pay to support me.	Apr 14, 2011 8:03 PM
4	respite care workers	Apr 15, 2011 7:51 AM
5	none	Apr 15, 2011 8:17 AM
6	We were able to hire our son's aide from school to help on occassion. Our parents are too old and do not know how to interact with him nor can they lift/transfer him (50#).	Apr 17, 2011 7:38 AM
7	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
8	school	Apr 18, 2011 1:31 PM
9	Once in a while my other daughter can watch my two children with special needs.	Apr 18, 2011 2:47 PM
10	school	Apr 19, 2011 4:11 PM
11	DSACO, autism group	Apr 19, 2011 5:01 PM
12	spouse	Apr 19, 2011 8:19 PM
13	Other parent of child with disability Occ with school employees	Apr 19, 2011 11:24 PM
14	Family will help on occassion or if Emergency	Apr 20, 2011 9:56 AM
15	Relative	Apr 20, 2011 7:36 PM
16	my son attends school daily and our older children care for him after school. Dont know what we'll do once they leave home.	Apr 21, 2011 8:01 AM

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 very self sufficient, and though at times the last 14 yrs have been difficult, we have managed without natural supports. It would be nice to have, but we do ok without.	Apr 14, 2011 11:28 AM
2	When Medicaid providers tell families to use "natural supports", it really means "thank you for doing my job while saving my company money."	Apr 14, 2011 12:09 PM
3	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
4	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
5	My husband and I moved here to start a business. All family is in another state and unable to help. Self employed people tend to be workaholics, not terribly social, so when first one then the other child were born with disabilities, we were isolated. Spent all our money getting early care for the first child and have had to close the business for lack of time to tend to it. Any assistance I get for either child -- even to have a moment to go to the grocery store -- is paid assistance. I think it's great that these questions are being asked. The natural support structure that was once in place in our society has deteriorated over the last 80 years. That obligation we once felt towards one another to help is gone. Everyone assumes the government should be doing it.	Apr 15, 2011 8:36 AM
6	While my daughter was developing language, there was no one that we could leave her with for time out as a couple or time with our other children. Now that she is a better advocate for herself as a young teenager, (and we can leave her alone with technology as a support) this isn't such a big issue, but like parents of any child with special needs, she doesn't have as much access to what's going on in life without us present. Eventually we found other parents of kids who are deaf/hard of hearing, who were a huge support to us, and now we offer that support to other families with younger kids. We did not find support at church (some amazingly ignorant responses from people there) or among our co-workers, and while both sets of extended family love her (and us) they live too far away to be a real support and have never learned how to communicate with her on a deeper level. I know this is minor compared to parents whose adult children require 24-7 supervision and assistance but wanted to add to the survey. Thanks for asking!	Apr 16, 2011 7:07 AM

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7	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
8	In our case the "natural" supports we receive are household chores help, 1-2 hr line of sight watching of our special needs child, and taking siblings of our special needs child to and from activities so I am free to care for my special needs child. It is a support, but it is not direct care of our special needs child for the most part. My parents, who are our "natural" supports are in their mid-seventies, so soon their own physical limitations will not allow them to even help us in the ways they do now.	Apr 16, 2011 1:39 PM
9	Natural supports are not an option for my son. He requires 24/7 line of sight care because he is non-verbal, mobile and lacks safety precautions. He requires assistance for all activities. Most adults - neighbors, family, friends - want easy "playdates" where the kids go play and they continue on with their adult duties. Natural supports are not an option for our situation.	Apr 17, 2011 7:38 AM
10	It is easier for us to use family members as supports since they live locally and have expressed their willingness to help out. I know many families for whom this is not the case. We don't have much extra money, so if a family member can't help us to watch kids, then we are rarely able to pay for babysitters and so don't go out in those cases.	Apr 17, 2011 2:57 PM
11	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
12	My disabled child is 10 and I am 47. I have two older sisters who are busy with their grandchildren. The idea of natural supports is great, but when you try to apply it you find there is no one who wants to get involved. They don't have the time, or they are afraid. Or any number of other reasons. So it's all left to me and my husband. It has wrecked my health.	Apr 18, 2011 7:43 AM
13	I wish I had natural supports. We have no family here and it is difficult for me to ask friends for help.	Apr 18, 2011 8:45 AM
14	I have reached out and found these supports. They do not spring up automatically. They take work to cultivate and nurture. It cannot be assumed that everyone has these, or is capable for forming these.	Apr 18, 2011 9:44 AM
15	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
16	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

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17	I think the other question is to define natural supports... parent support, respite care, understanding, help with other children, financial help... there are so many things families with special needs kids may need help with! While natural supports are sometimes available for me... I have had offers to have ladies from church come in and help with my son... My concern about using more of the natural supports I could use, is the negative impact it could have on my son and then in turn our family life. At this time and with his issues having multiple people helping care for him would not be helpful! It would require lots of time on my part to train caregivers for just a short time of help... Supports I do use are my parents, they will help with my other son; if they are not working! My church helps provide food for my family...	Apr 18, 2011 11:41 AM
18	Never heard of Natural Supports ? I have two kids on a IEP at school both have anxiety, depression, A.D.D. and they have to read out loud to learn and school teaching methods are not working so they read at 3rd level in the 7th and 10th grade	Apr 18, 2011 1:43 PM
19	I have been a parent of children with special needs for over 23 years, and I am a professional in the disability field, and I still do not understand what the term "natural supports" means exactly. I do not have extended family members to support me, and I do not have the funds to hire a live-in nanny, if that's what "natural supports" means. Therefore, I have very little support unless my college age daughter can watch the kids so I can get a short break.	Apr 18, 2011 2:47 PM
20	Just because I don't have any natural supports now doesn't mean I think they're a waste of time. Nonprofit organizations and advocates should be looking for ways to help families create natural support networks, not simply complain that because they are hard to develop then we should not bother. The reality is the federal and state budgets won't sustain everyone who needs help, so we better start finding alternative solutions.	Apr 18, 2011 3:50 PM
21	i am greatgrandmother of 12 yr. old boy. he has been entirely my responsibility since he was 6 months old. he has c.p , asbergers, & slight mr. he is my heart & i am so proud of him. at 72 i am terrified for him when i am gone.	Apr 18, 2011 5:12 PM
22	What I have learned is from other parents of children with disabilities.	Apr 18, 2011 6:44 PM
23	Though my child has several disabilities, the effects on her are at this time still mild compared to many others. Even so, we struggle to find her the help she needs. Our best support is one neighbor couple. Apart from them, we have few others to call for support.	Apr 18, 2011 8:20 PM
24	Accessing natural supports can be very difficult/unrealistic. Elderly grandparents may be unable to provide care, especially for a grandchild with significant physical disabilities. Aunts and uncles may live out-of-town, have work responsibilities or other challenges. Friends/neighbors may be intimidated by the responsibilities of caregiving, in that it may require lifting, toileting, alternative communication, health and safety precautions, etc. While it may be possible to access natural supports on an infrequent or emergency basis, ongoing access would likely be very difficult.	Apr 19, 2011 7:59 AM

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25	Last year we changed churches because there was little support where we were. As our daughter entered the church youth group the leaders were not willing to provide the supports she had received as a child in the children's program of the church. The church we sought and found has wonderful supports. She participates in the weekly youth group meetings and will go to summer camp with the group. A specific individual who is a behavioral assistant will be accompanying the group as a counselor, I didn't even have to request such support! I think supports can be found, however they are inconsistent and sometimes require major upheaval to the family. We are older parents with other grown children so they are also a support rather than a hindrance to seeking supports. They do have their own families, though, so we don't like to impose on them too much. Our daughter's girl scout troop has also been a good support. We used to pay someone to accompany the troop camping, but she has now camped twice with just the troop and leaders.	Apr 19, 2011 8:20 AM
26	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
27	Natural supports are not trained professionals and should not be used in place of them but rather in conjunction with them.	Apr 19, 2011 1:50 PM
28	My natural supports are very limited. My parents will not help at all, they feel that my child's disability is something he could "fix" if only he would try harder. My husband's mother helps occasionally but she is much older and truly no one else helps with my child. I would love to be able to rely on natural supports however, very few are educated on autism or care to take the time to be educated as it does not directly affect them.	Apr 19, 2011 3:27 PM
29	"Natural supports" are a blessing from God. What they do not provide so much that my son so desperately needs is more funding for things that insurance doesn't cover like homeopathic doctors, dietary supplements, professional childcare and certain effective, but costly interventions for children with autism.	Apr 19, 2011 4:11 PM
30	We need more information...that is correct from the state...which it seems the state doesn't know...about qualifying...and sooner than later.	Apr 19, 2011 7:23 PM
31	As supportive and lovely as friends and church are, they are not willing to enter in the world of lifting, diaper changes, medication administration, g-tube use, etc. that my son requires. To ask these folks to do so would be more than intrusive - it would be dangerous.	Apr 19, 2011 9:42 PM
32	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
33	"Natural supports" vary so widely from case to case and even within time frames that I don't believe that it is possible or fair for policy makers to use this notion as a basis for determining how funding for services is set.	Apr 20, 2011 9:40 AM
34	When someone (state workers) tell me that taking care of my child is my duty, I Cry. I need help. I try but get exhausted/sick or need to run errands. Can't. My family is strong, but not always available.	Apr 20, 2011 9:56 AM

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35	my parents are deceased and my hubands parents are elderly and cannot help.	Apr 21, 2011 8:01 AM
36	Our "natural supports" are primarily from involved grandparents. However, they are less able to help as they age and their health declines.	Apr 21, 2011 10:19 AM
37	<p>I think that "natural supports" are not reliable as a consistent way to provide services to people who have special health care needs or disabilities. Natural supports are just that, natural. But 'natural' doesn't mean 'ever-present' or 'consistent'. Rain is natural, but it doesn't rain every day. It also strikes me that 'natural supports' may mean different things to different families. I'll go one step further and say that the term "natural supports" is used to divert attention from the real issue of how much it costs to provide the services needed to care for people who have special health care needs and/or disabilities. In my situation, both of my parents are deceased. And even when my mother was living, I never will forget a statement that she made when she declined providing day care and babysitting for her first and only grandchild. She said "If love was enough, I would be able to do it. But my love is not enough." My adult sibilings live in distant states. My teenager has developmental, cognitive and physical disabilities. I work full-time because I have to. I am divorced with minimal connection with my ex. The people that I list as emergency contacts, are just that – call them only if I'm not available. And even then, I'd better be making my way toward the situation. Everyone in my neighborhood works full-time. I rarely have a chance to see my neighbors; let alone, ask them for a 'favor.' I don't attend church, as too many people stare or frown at the noises that come along with my teenager. We need neither pity nor unsolicited advice. What we need is practical help. Judgmental Christians are not helpful. In short, it's me and my kid. He's expensive, but he's mine. As these children grow into adulthood, they are even more expensive. Those adults in decision making positions, who have no clue what it takes to raise a child with special needs, see 'natural supports' as saving money in caring for these kids. My question to them is what (or who) are they saving the money for? In my world, 'natural supports' are non-existent. And since my teenager is somewhere on a waiting list for waiver services, practical help is pretty close to non-existent. Every service I have gotten has resulted from a hard-fought process. And just because a service is granted does not mean it will stay in effect. Re-determinations are constant. Vigilance is my companion when it comes to keeping services. And one must always be attentive regarding who is asking questions, why they are asking, how their questions are answered and by whom. As my teenager approaches adulthood, my growing worry is what will adulthood look like? What will happen when I die? In my experience, people may perform an occasional task out of the goodness of their heart, family obligation, a begrudging favor or, refreshingly, a true sense of altruism. "Occasionally" being the operative word. But even with that, I am grateful for the favor. On a daily basis and for the long term, the type of care needed by children and adults with disabilities requires money to pay caring, competent caregivers so that they can provide excellent, consistent, and dare I say, loving, care. For me, "natural supports" are not the answer.</p>	Apr 21, 2011 2:26 PM
38	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

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

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|----|--|-----------------------|
| 39 | natural supports imply that you are near family or others who are willing and interested and ABLE to handle the high demands of providing help with a child/adult that needs someone who knows how to handle and interact with them. How many people can you find who know what to do with a meltdown???How about a seizure???What if they think a "good hit to the backside" is the appropriate response??? | Apr 21, 2011 8:24 PM |
| 40 | I have to carefully consider when I ask family for help, because it comes with a price of their feeling entitled to be critical and give opinions. I also have to wait until I'm really desperate to ask for help, because otherwise, I am made to feel guilty for asking. | Apr 21, 2011 9:37 PM |
| 41 | The idea of "natural supports" is great if you have accessibility to them, unfortunately, as in my case there are none. I have a very small circle of family and friends, none of whom can be there for my son. I am a single mother, I work two jobs, my son has been on the waiting list for almost 8 years and I am barely making it. With the current economy everyone must work to survive. My son is a blessing and a joy but he is difficult to care for. It is almost impossible to get help in the community unless you can pay for it and I can not. I have liiked into programs and as soon as they hear of his disabilities I get the same response "We can't provide services to people with special needs" My son is unable to verbally communicate his needs and this truly scares people. There is not enough people familiar with this population to provide services. I have to fight tooth and nail just to keep my son in a public school-which is SUPPOSED to be a right by law. To those who have natural supports I comend them but it is just not a reality for a lot of people. | Apr 22, 2011 10:56 AM |