

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



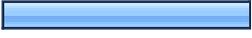
1. I am a		Response Percent	Response Count
Parent/guardian and caregiver of an individual(s) with a disability		81.5%	53
Parent/guardian of an individual(s) with a disability		13.8%	9
Caregiver of an individual(s) with a disability		1.5%	1
Individual with a Disability		3.1%	2
		answered question	65
		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		0.0%	0
15-19		100.0%	65
19-24		0.0%	0
25+		0.0%	0
		answered question	65
		skipped question	0

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

		Response Percent	Response Count
Physical disability		44.6%	29
Cognitive disability		86.2%	56
Mental Health Disability		33.8%	22
Other (please specify)		21.5%	14
		answered question	65
		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.)		40.0%	26
Neighbors		15.4%	10
Friends		36.9%	24
Church		18.5%	12
Social group		7.7%	5
None that I can think of		36.9%	24
Other (please specify)		20.0%	13
		answered question	65
		skipped question	0

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

		Response Percent	Response Count
Strong		13.8%	9
Moderate		20.0%	13
Little		20.0%	13
Miniscule		27.7%	18
No support from "Natural supports"		18.5%	12
answered question			65
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		29.2%	19
Sometimes		43.1%	28
Frequently		16.9%	11
A lot		10.8%	7
answered question			65
skipped question			0

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

		Response Percent	Response Count
I have received no such training		55.4%	36
I have received training and it has not been helpful		13.8%	9
I have received training and it has been somewhat helpful		26.2%	17
I have received training and it has been very helpful		4.6%	3
		answered question	65
		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
	39
answered question	39
skipped question	26

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

1	Behaviors with Agression, due to sever Autism	Apr 14, 2011 10:26 AM
2	apraxia, sensory integration disorder	Apr 14, 2011 12:00 PM
3	Multiple	Apr 14, 2011 4:55 PM
4	seizures	Apr 14, 2011 6:17 PM
5	Autism, severe behavioral challenges	Apr 15, 2011 7:27 AM
6	Autism. Hearing loss	Apr 17, 2011 9:36 PM
7	Autism	Apr 18, 2011 9:20 AM
8	emotional	Apr 18, 2011 1:59 PM
9	Autism, ADHD, Manic/ Depressive, OCD	Apr 18, 2011 2:07 PM
10	Visual Impairment, Epilepsy	Apr 19, 2011 4:08 AM
11	autism	Apr 19, 2011 7:34 PM
12	blind	Apr 20, 2011 8:24 AM
13	seizure and bowl disorder (hirshbrungs)	Apr 21, 2011 7:28 AM
14	Autism	Apr 21, 2011 6:32 PM

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	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
3	I am a single parent, minimal support from his father, no consistent dependable supports without assistance and I rely on hired caregivers.	Apr 14, 2011 12:00 PM
4	In the past, I had one friend that would help me in a crunch. She has returned to work now.	Apr 14, 2011 12:53 PM
5	Co-workers	Apr 14, 2011 4:55 PM
6	Since the only people who we feel can "handle" our son are all parent with their own special needs children, we cannot use them on a "regular" basis. They are our backup plan for when we can't find a paid caregiver. I think the definition of "regular" might need clarification which might help with the stats irregularity you mentioned on Pad-co. We have no family in Corado.	Apr 15, 2011 7:27 AM
7	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
8	People will help occasionally, but not regularly.	Apr 18, 2011 2:07 PM
9	the providers love the word "natural supports" . it's their way of not providing services. they are getting big bucks from the state and we are not getting the needed services. we are 76 and 78 yrs of age and are having a hard time when a worker does not show up.	Apr 18, 2011 2:30 PM
10	school	Apr 19, 2011 6:24 PM
11	only receive sporatic support, not regularly dependable or desirable.	Apr 21, 2011 2:01 PM
12	Paid sitters	Apr 21, 2011 6:32 PM
13	We have Mobile therapist, waiver support, and church people that are helpful with our son.	Apr 24, 2011 6:48 AM

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

1	They don't exist	Apr 13, 2011 8:25 PM
2	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
3	We get sympathy but no really help from family, friends etc. They think the gov't takes care of it all and have no clue.	Apr 14, 2011 6:37 AM
4	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
5	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
6	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

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

7	there are few if any inherent supports for the care of my 16 year old son with autism. Family and friends accept but can not assume responsibility for his care and well being. I could not function without paid assistance in the home..	Apr 14, 2011 12:00 PM
8	Most people are willing to help for a limited amount of time. No one would commit to long term help for a long term disability.	Apr 14, 2011 12:53 PM
9	We live in a different state than other family members so they are not able to help out on a daily or as needed basis. We do have friends in the area but they are busy with their own lives and it is difficult to depend on them for help except in short-term emergency circumstances.	Apr 14, 2011 1:05 PM
10	Even for families who have natural supports, they need a safety net system because those supports can wane as challenges with our kids grow.	Apr 14, 2011 1:26 PM
11	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
12	I have over 30 disabilities, and I'm only 18. So having natural supports helps me a lot. If it wasn't for my natural supports, I would have not graduated high school, & find and keep a full time job. The people who don't have disabilities need to know that natural supports & federal programs make us disabled people ABLE to function with little to no support.	Apr 14, 2011 4:55 PM
13	very hard to find people willing to help with little pay	Apr 14, 2011 6:17 PM
14	In our case, it was easier to use "natural supports " when we lived near family and our son was younger and easier to care for. At almost 19, and aggressive and destructive, with no family in the state, we have no option but to use paid support, every time we need to do something where our son's extremely unpredictable behavior could create difficulties.	Apr 15, 2011 7:27 AM
15	people in the community	Apr 15, 2011 11:58 AM
16	When kids are little, natural supports seem easier. When they enter middle school and beyond, it seems harder to find an KEEP them. Now as I look ahead to post high school support, I am fearful that all these supports I have in place will go away. in Reality, grandparents age and get sick or die, siblings go off to college and their own lives, as do age cohorts and friends...I wish I had known 5 years ago what kinds of employment development supports I would need for my child NOW. I would have done some things differrently in the transition part of my child's HS career.	Apr 15, 2011 2:01 PM
17	If perhaps I could get some support i wouldn't feel so burnt out!	Apr 15, 2011 5:48 PM
18	Nobody wants tohelp because the amount of work envolved with my child.	Apr 16, 2011 8:20 AM
19	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

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20	Other people have little patience in dealing with my son,thier relative because he is large and mentally young with sever autism,they are also unavailable as they already have to work alot.	Apr 16, 2011 4:44 PM
21	Should be an early childhood term only. The older a child gets the more natural supports disappear. Not there especiallyf for individuals with behavioral or medical needs.	Apr 17, 2011 9:36 PM
22	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
23	Natural supports would be wonderful if everyone did not have their own life with no time to help .	Apr 18, 2011 6:26 AM
24	I think we all want the best for our kids. I just wish they didn't make it so hard not to feel quilty and so expensive to get the help we need.	Apr 18, 2011 6:49 AM
25	Natural means unforced supports. It seems as though the state wants to force families to take care of a brother or relative whether they can or not.	Apr 18, 2011 9:20 AM
26	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 supose to be 'used' to it. What do you think the parent who is not acustomed 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
27	Natural supports come in a variety of ways. Your survey needs more open ended questions. Sometimes people try to be helpful and end up only adding stress to a situation. Others that totally understand, can be supportive just by not judging.	Apr 18, 2011 1:59 PM
28	Most of the support that my daughter has is my support. The other support systems available all cost extra money which I generally provide.	Apr 18, 2011 2:07 PM
29	when a provider takes on a client they should be prepared to furnish help that meets the needs of the client. the state dept. is too lenient on them.	Apr 18, 2011 2:30 PM
30	up until our school got into trouble we didnt even seperate the high school retards as they were called from the little ones.	Apr 18, 2011 3:21 PM

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31	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
32	Nonverbal, behavior issues, make it very difficult to find willing unpaid supports.	Apr 19, 2011 4:51 AM
33	It is very hard to find natural supports for a child with behavioral issues. I am lucky to have parents who live VERY close and can help me tremendously. If it wasn't for them my life would be very different.	Apr 20, 2011 8:24 AM
34	I think the earlier that you begin educating the community and developing the natural supports that your child the earlier. I think if they connect with your child when they are younger it is more successful.	Apr 20, 2011 2:02 PM
35	N/A	Apr 21, 2011 7:28 AM
36	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.	Apr 21, 2011 5:15 PM
37	I am not sure what natural support can, or are supposed, do to help me and my family	Apr 21, 2011 6:32 PM
38	Natural support is only from his grandmother; however, it is unrealistic to think that she will always be there or is always available. His brother lives in a different state. My sister has health issues of her own, my niece and nephew are heading off to college and his brother has been the only other natural support prior to moving. Natural support is not guaranteed and may not be consistent.	Apr 21, 2011 11:30 PM
39	As stated, communicating specific needs to the right person helps to provide the support when needed. We have some support friends with transportation, some supports for snow day sitters, others at church for the youth group/class sessions, and then the paid supports with wrap services, waiver with home and community supports for activities, and respite thru MHMR. We feel very fortunate to have all those willing to assist, and are very aware and thankful of each person's sacrifices. Communication is crucial.	Apr 24, 2011 6:48 AM