

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		69.4%	75
Parent/guardian of an individual(s) with a disability		19.4%	21
Caregiver of an individual(s) with a disability		3.7%	4
Individual with a Disability		7.4%	8
		answered question	108
		skipped question	0

2. The individual with a disability is the following age

		Response Percent	Response Count
0-4		2.8%	3
5-9		17.6%	19
10-14		16.7%	18
15-19		12.0%	13
19-24		15.7%	17
25+		35.2%	38
		answered question	108
		skipped question	0

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

		Response Percent	Response Count
Physical disability		42.6%	46
Cognitive disability		74.1%	80
Mental Health Disability		36.1%	39
Other (please specify)		29.6%	32
		answered question	108
		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.)		78.7%	85
Neighbors		14.8%	16
Friends		40.7%	44
Church		18.5%	20
Social group		12.0%	13
None that I can think of		0.0%	0
Other (please specify)		17.6%	19
		answered question	108
		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		100.0%	108
Little		0.0%	0
Miniscule		0.0%	0
No support from "Natural supports"		0.0%	0
answered question			108
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		47.2%	51
Sometimes		47.2%	51
Frequently		4.6%	5
A lot		0.9%	1
answered question			108
skipped question			0

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

		Response Percent	Response Count
I have received no such training		66.7%	72
I have received training and it has not been helpful		6.5%	7
I have received training and it has been somewhat helpful		17.6%	19
I have received training and it has been very helpful		9.3%	10
answered question			108
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
	59
answered question	59
skipped question	49

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

1	Type 1 Diabetes	Apr 13, 2011 10:23 PM
2	Difficult medical issues	Apr 14, 2011 9:16 AM
3	Speech impairment (nonverbal)	Apr 14, 2011 3:33 PM
4	Developmental disability	Apr 15, 2011 10:05 AM
5	deaf	Apr 15, 2011 5:25 PM
6	non verbal	Apr 15, 2011 6:45 PM
7	XXYY which affects him socially, intellectually, physically	Apr 16, 2011 6:05 AM
8	profound hearing loss	Apr 16, 2011 7:07 AM
9	visually impaired	Apr 16, 2011 8:15 PM
10	seizures	Apr 17, 2011 2:14 AM
11	mild cognitive and mental health disabilities and other health	Apr 17, 2011 8:32 AM
12	autism	Apr 17, 2011 2:57 PM
13	minimal brain damage due to abnormal chromosome along with non verbal learning disability	Apr 17, 2011 10:50 PM
14	social skills issues as well as behavioral.	Apr 18, 2011 7:16 AM
15	Severe Downs Syndrome	Apr 18, 2011 7:33 AM
16	Progressive/terminal neuromuscular disease	Apr 18, 2011 8:58 AM
17	severe anaphylactic food allergies	Apr 18, 2011 10:02 AM
18	emotional	Apr 18, 2011 1:59 PM
19	Special Health Care Needs also	Apr 18, 2011 3:33 PM
20	autism	Apr 18, 2011 3:42 PM
21	autism spectrum and muscular dystrophy	Apr 18, 2011 8:20 PM
22	xxyy syndrome, sympoms are severe speech difficulties, slight gross and fine motor difficulties, auditory memory problems.	Apr 19, 2011 4:04 AM
23	Cancer	Apr 19, 2011 5:55 AM
24	Health Disability	Apr 19, 2011 9:50 AM
25	Developmental Disability - Autism	Apr 19, 2011 11:16 AM
26	Rubinstein-Taybi syndrome	Apr 19, 2011 11:49 AM
27	Behavioral	Apr 19, 2011 1:14 PM
28	Suppressed immune system	Apr 19, 2011 3:23 PM

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

29	autism	Apr 19, 2011 6:11 PM
30	Uncontrolled seizures	Apr 19, 2011 10:03 PM
31	Profoundly hearing impaired	Apr 20, 2011 9:40 AM
32	seizure disorder	Apr 22, 2011 11:42 AM

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	Local support group	Apr 14, 2011 3:33 PM
3	Support from paid caregivers through our one of our state's Medicaid Home and Community-Based waiver programs. My son also receives some support from his co-workers.	Apr 15, 2011 7:39 AM
4	respite care workers	Apr 15, 2011 7:51 AM
5	my son resides in a group home, i am still involved in the crisis that occur	Apr 16, 2011 7:37 AM
6	My son's co-workers at his job at Walgreens provide natural supports so my son does not need a job coach.	Apr 16, 2011 9:07 AM
7	People who are employed by the park district where my son attends recreational activities. I pay them privately to provide respite for us in our home occasionally.	Apr 16, 2011 2:00 PM
8	personal support worker thru HBW	Apr 16, 2011 6:45 PM
9	College volunteers from a religious club	Apr 17, 2011 8:29 PM
10	I'm in a circle group	Apr 17, 2011 10:50 PM
11	My live-in attendant is paid for a certain number of hours every day and the rest of the care I require is covered as a "friend" or through room and board payment by me. I have quadriplegia with no functional movement in my arms or legs.	Apr 18, 2011 11:08 AM
12	Parent to Parent families	Apr 18, 2011 3:33 PM
13	Only have siblings as both parents are deceased and all siblings care for youngest who is disabled	Apr 19, 2011 1:14 PM
14	support groups	Apr 19, 2011 6:11 PM
15	school	Apr 19, 2011 6:24 PM
16	My famil members are sick and older than I am. I have to help them and my adult children with disabilities. My friends are in similar situations. Don't know how I am going to keep this up.	Apr 19, 2011 10:03 PM
17	Direct Support Worker	Apr 20, 2011 8:43 AM
18	disability community	Apr 23, 2011 12:30 PM
19	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	Our natural supports are older family members who may not be able to provide the support soon. Then we won't have anyone.	Apr 13, 2011 10:23 PM
2	This is the only way to go in the long term. Funding is inadequate or nonexistent, but relationships cultivated over time are what persists.	Apr 14, 2011 7:55 AM
3	There are people who feel and try to make us feel, as if our child with a handicap is our "lot if life" and we should just put up with it and not try to look for help, unless we pay for it. Of course the "child" they are talking about is 33, while they go about their business of vacations and tennis lessons.	Apr 14, 2011 8:18 AM
4	I fail to see the purpose in this poll. Insecure and indecisive parents will answer this poll negatively, and more initiative oriented people (such as me) will answer it neutrally or positively. It is inherently biased. Have classes in confident-building and problem solving.	Apr 14, 2011 11:15 AM
5	I do not have anyone who is a 'natural support' for the kind of home health specific support needed. That is primarily paid support. But do use natural supports for social and work experiences	Apr 14, 2011 2:08 PM
6	My biggest support is my close family and a couple of friends in emergencies. Mostly it is me and his step-father. We are lucky that our son does not have many health issues and can do much by himself, however he needs 24/7 supervision.	Apr 15, 2011 6:50 AM
7	While supports from family and friends has been important to my son and our families quality of life and connectedness, as my son has gotten older the "natural supports" don't seem so natural to him or me. As an adult he does NOT want to ask or rely upon his friends to provide for his "care". Rather he wants them to just be his friends. It is the same with family. While family members continue to provide a great deal of support for my son, we are all getting older AND my son does not get a real sense of independence when mother, daddy, brother, uncle, aunt and other relatives provide his support. I know several adults with disabilities that have similar feelings - they feel and are most independent and have a sense of dignity when there is a definite line between their "family relationships and friendships" and those that provide "care".	Apr 15, 2011 7:39 AM
8	We are extremely fortunate to have family close. If we ever move that support would dry up overnight.	Apr 15, 2011 10:05 AM
9	people in the community	Apr 15, 2011 11:58 AM
10	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
11	I have been blessed to live in an area that allows me (a parent) to be a paid caregiver. This has allowed my son, who has severe disabilities, with reliable, consistant, quality care! Of course, we have to stay on top of what's happening with legislation to be sure we don't lose this.	Apr 15, 2011 2:53 PM

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12	We used to live in Idaho, with family more than a day's drive away. We moved across country, closer to family, and yet grandparents are still one hour away. They help as they have time; still working. Other grandparents live 3 hours away, retired, and have no idea the work we go through for our son. Friends do not fully understand... Caring for our son with autism is a strain on our family, and on our marriage -- but, we would have it no other way. My husband and I often "tag-team" with our son, so time together to keep our marriage going is a commodity. Babysitters are not an option. Thankfully, we do have Personal Care Attendant hours, which help is giving me (Mom) a break. Still, PCA is not meant for babysitting, so does nothing for our marriage or family (we have 2 other children).	Apr 15, 2011 3:56 PM
13	only my mother provides support for my two 26 year old DD and deaf daughters. No other family members or friends have provided any actual help with daily care.	Apr 15, 2011 5:25 PM
14	For me, a lot of it comes down to my daughter's willingness to let me and her dad out of the picture and to willingly receive assistance from others we may recruit when we're tied up otherwise.	Apr 15, 2011 9:24 PM
15	Persons close to my family are loving and caring towards my son, but do not know how to help him socially or therapeutically.	Apr 16, 2011 6:05 AM
16	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
17	We have no extended family where we live. I have been informed as to where to find Personal Service Workers, but have not followed through at this time. I rely on my sons' older sister as a natural support. It would be a big step for me to reach out to other people as would be required to form a Microboard or on a smaller scale to find personal service workers.	Apr 16, 2011 9:07 AM
18	Natural supports are very difficult, if not impossible to develop. We are fortunate that through our son's volunteer job, he has a number of fiends at work; but the support ends at the end of the work day.	Apr 16, 2011 11:54 AM

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19	My son is 34, uses a wheelchair, needs to be fed, bathed, toileted, etc. He is very communicative by voice (severe dysarthria) or Dynavox. Has a great sense of humor! Family members are busy people also, and I am uncomfortable asking anyone but siblings to help out. I offer to pay my niece or nephew, but siblings and one aunt help on occasion for free. Not all friends or relatives are comfortable or interested in helping. Even finding paid help is uncomfortable for me, as that means finding someone who we can trust alone with our son in our house. We've had some bad experiences over time. Luckily, we have a wonderful caregiver who is here while we are at work. This is her 10th year with us! I feel it is important to have both natural supports and financial assistance through state programs available. Without them many families would have too much stress, both emotional and financial.	Apr 16, 2011 2:00 PM
20	I developed natural supports on my own instead of a training	Apr 16, 2011 4:35 PM
21	We don't receive any paid supports so we've been forced to get creative. Our 8 year old daughter is non-verbal and medically complicated with multiple disabilities. Her friends have become great natural supports both at school and here at home. They play together at our home which frees me up to do chores, and they go on errands and trips with us. I really hope we can keep this going over time.	Apr 16, 2011 6:37 PM
22	Care providers are threatened by these supports.	Apr 16, 2011 8:15 PM
23	I am a single parent-there is not enough time in the day or lifetime to do it all. I guess I don't have as many friends or neighbors as those who promote/prag about the natural supports they have established for their child - my friends and neighbors also have a lot on their plates... A typical parents fear would be that they survive their child - as terrible as it sounds I am afraid that my child will survive me - my nightmare is the image of my woman child (unmedicated) living on the streets, pushing a grocery cart loaded with her most precious toys. Having said this, I am incredibly fortunate to have a nephew with a gentle heart, who has clearly asserted that my daughter will not live with strangers rather she will live with him, his wife and child(ren) - therefore I have named him as the beneficiary for my retirement monies once I am dead (50% for his lifetime) and he will also inherit my house to live in or sale - in the end it is a "crap shoot" - however, I believe that I trust his intentions over the intentions of any agency or beurocracy.	Apr 17, 2011 8:32 AM
24	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

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25	As my son has gotten a bit older and has become more manageable, I am better able to rely on family and even occasionally ask something of friends and neighbors. When my son was hospitalized the first time, neighbors told me that their church group prayed for him and this continued for years as he never recovered. Friends cooked us meals but this dropped off as it became less of a crisis and more of a sad but everyday reality. From a research prospective I feel that this survey has an inherent bias and anger towards "the system" for trying to substitute free natural supports for state provided services. With that, even if your survey supports your premise that natural supports are lacking and insufficient to substitute, I don't think anyone from "the system" would find your survey methods credible or valid, just by the way your questions are phrased and leading. Though I appreciate your efforts!	Apr 17, 2011 8:29 PM
26	i'm interested in doing public speaking	Apr 17, 2011 10:50 PM
27	we have had "natural support" from grandparents, but they are now aging to the point they require support instead of being able to provide assistance. since we depended on them so much for years, we never really developed other "natural supports" of friends, etc..... and since having a DD child, our circle of friends has narrowed drastically.....	Apr 18, 2011 6:41 AM
28	We as parents should have special training classes for our natural supports so that they could have a better impact.	Apr 18, 2011 7:16 AM
29	While being on the Wait~List for several years now, I don't know what I would do without family support!	Apr 18, 2011 7:23 AM
30	with out my church I would have none..not sure where to look for them	Apr 18, 2011 7:26 AM
31	I utilize my adult daughter as my natural support but this takes a toll on her as well. We have other children but very seldom are we able to "go out" for a "family" function. Our daughter is medically fragile and thus cannot travel very well. My adult daughter also helps me care for my younger disabled daughter with things such as bath time. I cannot lift my 80 pound child by myself. Sometimes I worry about the load that I have placed on her but I do not know what else to do or who else would help.	Apr 18, 2011 8:58 AM
32	Natural supports is a wonderful concept but many times it does not happen. Some people including family members are not comfortable being responsible for a person with developmental disabilities.	Apr 18, 2011 9:25 AM
33	Food allergies are still not very well known and people don't understand their severity and that they are a disability, even to those closest to you, your "natural supports." It is hard to trust other people, even those closest, to really understand how to keep your child safe. It means that my husband and I rarely get to do things outside of our home and taking care of our child. There are very few support groups for food allergies and little to no "training." What you learn you have to seek out yourself.	Apr 18, 2011 10:02 AM
34	I feel like I can rely on support from friends for simple tasks, but not for anything major.	Apr 18, 2011 11:08 AM

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35	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
36	Big difference between support and help. Hard to answer because on one hand we have recieved much support from other parents over the years and help from Parent to Parent- like Person Centered planning etc. But no real "help" in the day to day activities for our daughter with a disability. It is my husband and I and her the staff we pay for.	Apr 18, 2011 3:33 PM
37	My parents are older and won't we able to help much longer. Then we will have no one. We are on AR waitlist.	Apr 18, 2011 3:42 PM
38	So called "natural supports" are fine as a back-up, but as individuals with disabilities age, that support disappears. As parents/caregivers age, they have less and less access to true support for an adult child with significant challenges. This is NOT a solution, or a replacement, for paid community support from caregivers who are trained and understand the expectations of individuals with disabilities and their families who have a right to an independant life.	Apr 18, 2011 7:35 PM
39	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
40	Partners in policymaking training was helpful to me as a parent We learned how to build social Capital with and for our kids	Apr 19, 2011 6:04 AM
41	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 inconsistant 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 hinderance 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
42	I don't have many natural supports for my son. This idea is ridiculous.	Apr 19, 2011 9:02 AM
43	I believe we all use and need natural supports in our life. While it might be great to be totally independent and do everything on our own life is always like that. Instead of thinking we are a burden to our families we must think of these relationships different through a give and take system. I use my family for personal care but I then turn around and help them with tasks that they need help with. In this way we become a stronger family.	Apr 19, 2011 12:59 PM

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44	The siblings make huge sacrifices to care for youngest who os on waiting list. There are no other options and the state gets away with doing nothing despite waiting list issues. Stipend proposal is joke. Try and find a caregiver for a weekend. What universe do these DDD so called experts live in ? I hope they become home bound some day and someone offers to give them money for a caregiver. Will that person grocery shop and do laundry and care for their ailment? These people have their heads in the sand	Apr 19, 2011 1:14 PM
45	It is very hard to ask from natural supports-- I feel as if it is a hardship on them to help out esp. for no pay. Asking them to take on a lot of responsibility.	Apr 19, 2011 1:19 PM
46	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
47	I receive good emotional support from church, friends, and support groups but very little practical support. Another question you might have asked is, what kinds of support do you receive from "natural supports."	Apr 19, 2011 6:11 PM
48	Partners in policymaking training was helpful to me as a parent We learned how to build social Capital with and for our kids	Apr 19, 2011 6:18 PM
49	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
50	My 'natural support' is my own mother who is now over 65. She is the only other person who will watch my son with moderate autism. I am a single mom with no other help. I am also disabled and my mother doesn't drive. Natural supports only works with lots of family or if you have money and lots of time to train people.	Apr 19, 2011 10:02 PM
51	As I age along with my children, so do my friends and my natural supports are dwindling. So many of us are too old to maintain the level of assistance that my children need as they continue to age. Where are the long term supports when we no longer can provide the care for our children.	Apr 19, 2011 10:03 PM
52	"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
53	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
54	Without "natural supports" when it comes to mental health it is nearly impossible. The availability of affordable mental health care is sad.	Apr 21, 2011 12:36 PM
55	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
56	the current natural supports are going off to college and are aging. They have provided backup and emergency coverage when needed. Other "natural" supports become un-natural when used repeatedly and with intensity.	Apr 22, 2011 11:42 AM

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57	My son would much rather be with those who want to be with him, not those who have to be paid to do so. We need to work together so there will be funding to help more.	Apr 22, 2011 4:02 PM
58	natural supports should never be used to reduce paid supports, if we ask friends and neighbors to help PWD with activities of daily living and instrumental activities of daily living those supports will go away	Apr 23, 2011 12:30 PM
59	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