

# 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		91.9%	57
Parent/guardian of an individual(s) with a disability		6.5%	4
Caregiver of an individual(s) with a disability		1.6%	1
Individual with a Disability		0.0%	0
		<b>answered question</b>	<b>62</b>
		<b>skipped question</b>	<b>0</b>

2. The individual with a disability is the following age		Response Percent	Response Count
0-4		0.0%	0
5-9		100.0%	62
10-14		0.0%	0
15-19		0.0%	0
19-24		0.0%	0
25+		0.0%	0
		<b>answered question</b>	<b>62</b>
		<b>skipped question</b>	<b>0</b>

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

		Response Percent	Response Count
Physical disability		43.5%	27
<b>Cognitive disability</b>		<b>72.6%</b>	<b>45</b>
Mental Health Disability		32.3%	20
Other (please specify)		33.9%	21
		<b>answered question</b>	<b>62</b>
		<b>skipped question</b>	<b>0</b>

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

		Response Percent	Response Count
<b>Immediate extended family (brothers, sisters, grandma, etc.)</b>		<b>59.7%</b>	<b>37</b>
Neighbors		8.1%	5
Friends		25.8%	16
Church		14.5%	9
Social group		9.7%	6
None that I can think of		25.8%	16
Other (please specify)		6.5%	4
		<b>answered question</b>	<b>62</b>
		<b>skipped question</b>	<b>0</b>

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

		Response Percent	Response Count
Strong		14.5%	9
Moderate		30.6%	19
<b>Little</b>		<b>32.3%</b>	<b>20</b>
Miniscule		14.5%	9
No support from "Natural supports"		8.1%	5
<b>answered question</b>			<b>62</b>
<b>skipped question</b>			<b>0</b>

**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
<b>Never</b>		<b>40.3%</b>	<b>25</b>
Sometimes		37.1%	23
Frequently		14.5%	9
A lot		8.1%	5
<b>answered question</b>			<b>62</b>
<b>skipped question</b>			<b>0</b>

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

		<b>Response Percent</b>	<b>Response Count</b>
<b>I have received no such training</b>		<b>80.6%</b>	<b>50</b>
I have received training and it has not been helpful		3.2%	2
I have received training and it has been somewhat helpful		14.5%	9
I have received training and it has been very helpful		1.6%	1
		<b>answered question</b>	<b>62</b>
		<b>skipped question</b>	<b>0</b>

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

	<b>Response Count</b>
	32
<b>answered question</b>	<b>32</b>
<b>skipped question</b>	<b>30</b>

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

1	autism	Apr 14, 2011 12:08 PM
2	Developmental disability	Apr 15, 2011 10:05 AM
3	autism, i don't consider it mental health	Apr 15, 2011 3:14 PM
4	PDD-NOS, ASD	Apr 15, 2011 3:52 PM
5	XXYY which affects him socially, intellectually, physically	Apr 16, 2011 6:05 AM
6	Epilepsy, Lennox-Gaustat Syndrome	Apr 17, 2011 10:58 AM
7	social skills issues as well as behavioral.	Apr 18, 2011 7:16 AM
8	Progressive/terminal neuromuscular disease	Apr 18, 2011 8:58 AM
9	Autism- a Developmental Disability	Apr 18, 2011 9:22 AM
10	social, communication disability	Apr 18, 2011 9:59 AM
11	SLI	Apr 18, 2011 10:47 AM
12	autism	Apr 18, 2011 3:42 PM
13	ADHA	Apr 18, 2011 5:43 PM
14	xxyy syndrome, sympoms are severe speech difficulties, slight gross and fine motor difficulties, auditory memory problems.	Apr 19, 2011 4:04 AM
15	Health Disability	Apr 19, 2011 9:50 AM
16	Developmental Disability - Autism	Apr 19, 2011 11:16 AM
17	Developmental disability	Apr 19, 2011 1:31 PM
18	Autism	Apr 19, 2011 2:01 PM
19	Suppressed immune system	Apr 19, 2011 3:23 PM
20	Down Syndrome	Apr 19, 2011 3:24 PM
21	Behavioral	Apr 21, 2011 8:11 AM

**Q4. Choose all that apply:**

**I have "natural supports" that I can regularly depend on to help from the following:**

1	definition of natural supports would be great at the beginning of the survey. my answer is in regards to "regularly depend on". we do get free respite from a non profit group monthly but not srue if it qualifies.	Apr 15, 2011 3:14 PM
2	Babysitters can handle her physically after surgery like now. Most of the time, grandparents can help but not during times when she is more physically dependent.	Apr 16, 2011 11:02 AM
3	College volunteers from a religious club	Apr 17, 2011 8:29 PM
4	I have some (little) natural supports that I don't have to pay out of pocket for. Most supports from friends who assist with babysitting/respite I have to compensate them.	Apr 18, 2011 1:17 PM

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

1	The school system should be a natural support since my child spends 8 hours a day there, 5 days a week. "In loco parentis" doesn't seem to apply to many school officials.	Apr 13, 2011 9:51 PM
2	People are willing to help on occasion, but on occasion help is not properly trained and cannot remember specifics between time to time. Most people are already VERY busy with their own lives, in school, working extra hours to pay for increasing prices lately of gas etc and can't afford to give regular time and help.	Apr 15, 2011 8:54 AM
3	We are extremely fortunate to have family close. If we ever move that support would dry up overnight.	Apr 15, 2011 10:05 AM
4	it would have been nicer to be able to choose from multiple ages since i have more than one with a disability. if the gov't wants to push people to use natural supports which i believe means family and friends (if you're lucky to have them) instead of agencies, you might as well provide more mental health benefits because a lot of people are going to go crazy and depressed etc.	Apr 15, 2011 3:14 PM
5	As a military family, we are far from extended family who would otherwise be "natural supports" and I have only asked friends to care for my child during moves.	Apr 15, 2011 3:52 PM
6	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
7	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
8	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
9	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

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10	I, myself, am a mother with significant CP, and I have two children. No family in CO. As my daughter's seizures and other delays progress, my friends become less willing to assist. I use attendants to meet my own needs, but I find it increasingly difficult to even shower, because there is no one to supervise my daughter. Medical Needy kids and "natural supports" is often not practical.	Apr 17, 2011 10:58 AM
11	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 perspective 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
12	no comments now.	Apr 18, 2011 6:57 AM
13	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
14	It is hard for natural supports to know how to handle our child at times.	Apr 18, 2011 8:08 AM
15	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
16	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
17	Think school system may have a tendency to over-rely on natural supports in lieu of providing appropriate services, referrals, accommodations, and modifications. Also, People with Disabilities (and Parents/Caregivers) should receive more info. training about natural supports (training/gaining), as well as, terms that imply/refer to these concepts. Thanks to Carol Calix of Families Helping Families (NOLA) for sharing this Denver Fox, EdD. insightful natural supports survey.	Apr 18, 2011 9:22 AM
18	I don't think natural supports should replace in-home community based services. Thank god our relatives will provide some supports but if we went back to that well continuously or without compensation it would dry up fast. We still need community based services (fee based) to supplement natural supports. Remember it takes a village to raise a child with special needs.	Apr 18, 2011 1:17 PM
19	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

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

20	Full time grad student and never heard "natural support", very poor support group for diwn syndrome in Shreveport	Apr 18, 2011 4:07 PM
21	We've settled in Colorado many states away from extended family, but even if we lived near, they would not be able to help in a significant way. "Natural supports" sounds very scary to me. My kiddo currently has OT, PT, speech, and a g-tube, no one in our lives is currently able to do this in any form "naturally." If we all had these "natural supports" would there be any need to train paid professionals? And I also think about when my daughter gets older and much less cute, who's going to help out then? When I can't carry her anymore.	Apr 18, 2011 11:03 PM
22	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
23	Having natural supports that truly want to be involved in the care of your loved one is a rarity.	Apr 19, 2011 7:20 AM
24	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
25	I don't have many natural supports for my son. This idea is ridiculous.	Apr 19, 2011 9:02 AM
26	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
27	Friends and family, while having good intentions, are not qualified to care for our child and have shown poor understanding of his disability. After "help" from natural supports, I always feel a bit beat up. I would much rather pay someone.	Apr 19, 2011 1:31 PM
28	I believe we should look to ourselves and our immediate and extended family and friends before looking to the government for support for our unique blessings.	Apr 19, 2011 3:24 PM

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- 29 Individuals with disabilities and to a lesser extent their families are isolated by the challenges created by the disability (i.e. their ability to interact with others, participate in activities with others, and share common interests with others. By its nature a disability will create challenges that others do not face, do not understand, and many times are not interested in understanding since it does not effect their lives or those of their loved ones. The limitations created by a disability and the time required to cope with them, contribute to significant isolation of individuals with disabilities, resulting in far fewer friends and acquaintances. Many times the friends they do have also have disabilities, so they would not be able to provide supports since they require them also. This is very well documented in studies of individuals with disabilities that they have far fewer friends and acquaintances are much more isolated than the average individual who does not have a disability. The same tends to be true for their parent caregivers to a lesser extent. Due to the significant demands placed on them to care for their loved ones they have far less time, energy, and resources to pursue relationships with others. This also means they have less in common with individuals in typical families which is often a factor in building relationships with others. Therefore, they have fewer friends and acquaintances themselves. The idea of relying on "natural supports" that are non existent would be laughable if it wasn't so sad. Why would anyone think an acquaintance would want to shoulder the responsibility and burden of caring for an individual with a disability when many state and Federal programs are failing to do so. I don't think the parent caregivers would volunteer to provide "natural supports" to non family members if they were given the choice. However, they do so out of love for their children, and without adequate support from Federal or state programs, or the non existent "natural supports" , they do so to the detriment of their own health and well being. The constant demands of their loved one's disability and the never ending fight for supports from indifferent government officials and programs that don't really care about the needs of the individual with a disability or their family take a heavy toll and have no end. This is the reality of life for a parent/caregiver. What fool thinks an acquaintance would be eager to accept the responsibility or the stress the parent / caregiver shoulders? And we haven't even gotten to the gnawing sense of fear and doom that many of us face knowing that no one else will fill the void for our loved ones after we are gone. I think the idea of relying more on "natural supports" in lieu of Federal and state programs to support individuals with disabilities is just a theory invented by those who seek to cut desperately needed services for individuals with disabilities, but having a conscience and can't bear to face the consequences, so they pretend non existent and illogical "natural supports" will materialize to prevent them. To those who consider this path I offer what Our Lord said in Matthews 25:40 "The King will reply,'I tell you the truth, whatever you did for one of the least of these brothers of mine, you did for me. And at 20:45 "He will reply,'I tell you the truth, whatever you did not do for one of the least of these, you did not do for me.' I can only pray that either concern for their conscience or their eternal salvation will sway them from this path. There is a lot at stake here.
- Apr 20, 2011 12:31 PM
- 30 In Oklahoma any supports are very hard to find. private/public Childcare are often times not sensitive to children with disabilities. And financial assistance for therapy and support help is non existent for those parents who work. Unless you have family in town that can help, many parents are having to quit their jobs to care for their children in order to receive financial support from the state. Natural supports are rare. We depend on the public schools, church, and intermediate family. Natural supports, any supports are rare and we just do what we can, which most times are lacking and insufficient.
- Apr 21, 2011 3:51 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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|----|--|-----------------------|
| 31 | 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. | Apr 21, 2011 6:34 PM  |
| 32 | Natural Supports is a term that the government has come up with. Outside family members have no responsibility to help care for children with disabilities.                | Apr 22, 2011 11:26 AM |