

# 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		86.0%	92
Parent/guardian of an individual(s) with a disability		7.5%	8
Caregiver of an individual(s) with a disability		3.7%	4
Individual with a Disability		2.8%	3
<b>answered question</b>			<b>107</b>
<b>skipped question</b>			<b>0</b>

## 2. The individual with a disability is the following age

		Response Percent	Response Count
0-4		5.6%	6
5-9		18.7%	20
10-14		19.6%	21
15-19		12.1%	13
19-24		18.7%	20
25+		25.2%	27
<b>answered question</b>			<b>107</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		44.9%	48
<b>Cognitive disability</b>		<b>71.0%</b>	<b>76</b>
Mental Health Disability		29.0%	31
Other (please specify)		30.8%	33
		<b>answered question</b>	<b>107</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>49.5%</b>	<b>53</b>
Neighbors		8.4%	9
Friends		29.0%	31
Church		13.1%	14
Social group		7.5%	8
None that I can think of		14.0%	15
Other (please specify)		18.7%	20
		<b>answered question</b>	<b>107</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		0.0%	0
Moderate		0.0%	0
<b>Little</b>		<b>100.0%</b>	<b>107</b>
Miniscule		0.0%	0
No support from "Natural supports"		0.0%	0
<b>answered question</b>			<b>107</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
Never		29.9%	32
<b>Sometimes</b>		<b>57.0%</b>	<b>61</b>
Frequently		8.4%	9
A lot		4.7%	5
<b>answered question</b>			<b>107</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>76.6%</b>	<b>82</b>
I have received training and it has not been helpful		7.5%	8
I have received training and it has been somewhat helpful		13.1%	14
I have received training and it has been very helpful		2.8%	3
		<b>answered question</b>	<b>107</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>
	63
<b>answered question</b>	<b>63</b>
<b>skipped question</b>	<b>44</b>

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

1	Asperger's	Apr 14, 2011 11:13 AM
2	Non Verbal, and uses a wheelchair	Apr 14, 2011 3:37 PM
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	deafblind,cerebral palsy-tactile sign and read/write Braille	Apr 17, 2011 5:20 AM
6	autism	Apr 17, 2011 8:02 AM
7	Epilepsy, Lennox-Gaustat Syndrome	Apr 17, 2011 10:58 AM
8	Autism. Hearing loss	Apr 17, 2011 9:36 PM
9	Global developmental delay (all in all)	Apr 18, 2011 7:21 AM
10	Down Syndrome, both mental and physical	Apr 18, 2011 8:01 AM
11	Autism	Apr 18, 2011 9:20 AM
12	Autism- a Developmental Disability	Apr 18, 2011 9:22 AM
13	SLI	Apr 18, 2011 10:47 AM
14	Autism Spectrum Disorder (PDD-NOS), Learning Disability	Apr 18, 2011 11:41 AM
15	some behavioral problems-temper tantrums	Apr 18, 2011 12:57 PM
16	Autism, ADHD, Manic/ Depressive, OCD	Apr 18, 2011 2:07 PM
17	Autism, Down syndrome, amputee and medically fragile	Apr 18, 2011 2:47 PM
18	Fragile X Syndrome	Apr 18, 2011 6:44 PM
19	vision impairment	Apr 18, 2011 9:25 PM
20	specific learning disability	Apr 18, 2011 9:49 PM
21	Autism	Apr 19, 2011 9:54 AM
22	Developmental disability	Apr 19, 2011 1:31 PM
23	Autism	Apr 19, 2011 3:27 PM
24	autism	Apr 19, 2011 7:34 PM
25	special health care needs	Apr 19, 2011 9:42 PM
26	I have two adopted children with severe disabilities	Apr 20, 2011 9:56 AM
27	Autism, Tuberous Sclerosis	Apr 21, 2011 6:23 PM
28	severe sensory issues	Apr 21, 2011 7:36 PM
29	vision, endocrine, more	Apr 21, 2011 9:37 PM

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

30	medically fragile, chronic lung disease	Apr 22, 2011 12:29 AM
31	at the moment, she seems to have an undiagnosed depression.	Apr 22, 2011 1:51 PM
32	autism	Apr 22, 2011 8:52 PM
33	developmental disability	Apr 25, 2011 9:12 AM

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

1	ex-husband	Apr 13, 2011 8:24 PM
2	Now--spouse. 10 years ago, none	Apr 14, 2011 11:13 AM
3	I have all of the above, but not anyone that can or will provide direct services or supervision for my son.	Apr 14, 2011 11:20 AM
4	We have a school aide that we can use occasionally.	Apr 14, 2011 3:37 PM
5	I have family but I can't regularly depend on them	Apr 14, 2011 9:29 PM
6	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
7	synagogue	Apr 17, 2011 5:20 AM
8	I receive a limited amount of help from church, neighbors, and friends - my closest friends are also caregivers of children with disabilities, which greatly limits the amount of support they can provide.	Apr 17, 2011 12:10 PM
9	1 grandmother 2x a year.	Apr 18, 2011 7:21 AM
10	Our Daughter	Apr 18, 2011 8:21 AM
11	Son's dad who is a co-guardian	Apr 18, 2011 10:45 AM
12	we have family and friends supports but cannot rely on them "regularly", only occasionally.	Apr 18, 2011 12:57 PM
13	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
14	People will help occasionally, but not regularly.	Apr 18, 2011 2:07 PM
15	Once in a while my other daughter can watch my two children with special needs.	Apr 18, 2011 2:47 PM
16	my mom but she works and has been sick	Apr 20, 2011 9:14 AM
17	Family will help on occassion or if Emergency	Apr 20, 2011 9:56 AM
18	Relative	Apr 20, 2011 7:36 PM
19	ACAP-adult community autism program, lget no support from any other of the above	Apr 21, 2011 7:36 PM
20	Younger adult sibling living in home who works, attends school, and has social life. Brother (much older with health issues) provides support in community with volunteer work. Sister lives out of state, older son lives out of town.	Apr 23, 2011 1:27 AM

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

1	The infrequency of natural supports in the distant past was never assured. Now, those infrequent supports have left our lives completely and it is assured they will not provide any support.	Apr 13, 2011 8:24 PM
2	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
3	The concept of natural supports assumes that relatives live nearby and that parents/guardians have lots of time and opportunities to cultivate relationships outside of the household. It also assumes that the natural supports have time to give--not necessarily true if they have demanding jobs, their own children, or elderly relatives.	Apr 14, 2011 6:56 AM
4	My nearest immediate extended family is one hour away, which makes it only useful for occasional help, but certainly not helpful for daily care issues. And not at all reliable when the weather and roads are bad! It's hard to find friends who are willing or able to help take care of my daughter with their busy lives.	Apr 14, 2011 8:55 AM
5	Would have loved natural or unnatural support. I had no respite care, no competent after school care.	Apr 14, 2011 11:13 AM
6	I found this hard to do. I have a lot of people who support ME to support my son, but no one who is available to provide direct support to him.	Apr 14, 2011 11:20 AM
7	Family have proven unwilling and unable to assist competently with any level of care. Neighbors and others who are not professional caregivers are not consistently available in our situation despite our participation in a close knit community that creates a lot of natural supports for non-disabled children and community members.	Apr 14, 2011 12:20 PM
8	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
9	It takes a lot of work to use "natural supports" ie friends, family to provide care to our son. They are willing but it takes a lot of planning and our son is not always comfortable with the care they provide. He is safe with them but they don't do things the way he is used to them being done, thus creating him to worry more.	Apr 14, 2011 3:37 PM
10	It seems that everyone is taxed including those who do not have individuals with disabilities in their lives. Being able to ask people to add more to their plate isn't always easy for me.	Apr 15, 2011 5:56 AM
11	Our natural supports are there in case of an emergency. These are not supports we use on a regular basis, nor do we expect them to help us with our ongoing needs with our son.	Apr 15, 2011 7:59 AM
12	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

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13	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
14	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
15	If perhaps I could get some support i wouldn't feel so burnt out!	Apr 15, 2011 5:48 PM
16	It was easier when he was a little guy. Then it was just "babysitting" even though he was 10 or 12 at the time. Once the puberty happened and he was trapped in the world of no age ( still likes things that 8-10 year olds like but is 22) there are no natural supports unless there is money or some reward provided. No one knows how to deal with him. People at church love him at church but there is no activities outside that venue. The people he works with love him but don't socialize with him outside of work. He still has some friends from school that will come to visit him if we have a party at our house or some venue in Denver, but no socializing or anything from them spontaneously or no inclusion in activities they are doing anyway. So tell me what are his natural supports and how do we access them??? I think money is the only language that is spoken in "natural support land"	Apr 15, 2011 8:52 PM
17	I took care of my son at home for over 30 years before he entered a group home. "Natural supports" sounds like the state is trying to duck its responsibilities. State governments need to step up and stop throwing our kids under the bus in the name of budget cuts.	Apr 16, 2011 7:15 AM
18	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
19	natural supports have not helped me. they love my son but are not, will not, and cannot be responsible to support me in daily weekly living events and situations. No one I know is in a position to take on added responsibility to support someone outside their own family.	Apr 16, 2011 10:41 PM
20	too few people fluent in sign, no funds for interpreters people want my child for photo ops, not providing ongoing support I am single parent, working FT my child has suffered physical and verbal (sign) abuse from 2 different caregivers	Apr 17, 2011 5:20 AM
21	What bothers me about the term "natural supports" is that the state uses it to justify providing the minimum amount of services possible. What is natural about parents having to provide LTC & financial support for their adult children throughout their lifespan & into old age? We do it because we love our kids & want the best for them, but it takes a toll. And where is OUR natural supports? This week I will take a 3-day vacation without dear son for the first time in 23 years. Twenty-three years - what is natural about that?	Apr 17, 2011 7:40 AM

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22	Natural supports are only really available on a once in a while need, but noone in our 'natural support' system would be willing to take on full time care.	Apr 17, 2011 8:02 AM
23	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
24	I like the concept of natural supports, but it's much more difficult for some to develop than others. My adult daughter has very limited communication, several personal care/health needs, and unusual behaviors (very stressed by new situations/changes in routine; when really upset, may hurt herself or others) and we've moved a number of times due to job changes/layoffs. Her only sibling is in the military (out of state and soon to be deployed overseas); our nearest relatives are 10 hours away. Most of our friends are other families with children with disabilities, so their help is limited. It was much easier to find supports for her when she was a cute/quirky 3-year-old (her disorder has been regressive; she has many more needs now); a few people have offered help but I am not sure they could safely manage my daughter.	Apr 17, 2011 12:10 PM
25	Should be an early childhood term only. The older a child gets the more natural supports disappear. Not there especially for individuals with behavioral or medical needs.	Apr 17, 2011 9:36 PM
26	no comments now.	Apr 18, 2011 6:57 AM
27	I feel that most "Natural Supports" don't really understand "how" to help. they either step in and do things without asking assuming you need the help (you would just like some assistance) or they don't even offer help or they don't understand the level of help you aer trying to explain to them, so usually I struggle with it myself.	Apr 18, 2011 7:35 AM
28	Afraid to use natural supports from Churches. All my older kids were sexually abused in a Church on a systematic level without my knowledge at the time.	Apr 18, 2011 8:01 AM
29	It is hard for natural supports to know how to handle our child at times.	Apr 18, 2011 8:08 AM
30	Until we can make people with Developmental Disabilities a "Fabric of each Community" natural supports will be an intangible that we are always looking for but will very rarely be available.	Apr 18, 2011 8:21 AM
31	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
32	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 Familes (NOLA) for sharing this Denver Fox, EdD. insightful natural supports survey.	Apr 18, 2011 9:22 AM

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33	Though I've had training, his father hasn't had & doesn't care too; which puts stress on my life as he doesn't always get what he's supposed to. Have had other people taking care of our son, which has been minimally beneficial.	Apr 18, 2011 10:45 AM
34	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
35	The need for any supports either paid or natural will increase as we age and die leaving our son relying totally on others for his care.	Apr 18, 2011 12:57 PM
36	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
37	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
38	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
39	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
40	Full time grad student and never heard "natural support", very poor support group for diwn syndrome in Shreveport	Apr 18, 2011 4:07 PM
41	What I have learned is from other parents of children with disabilities.	Apr 18, 2011 6:44 PM
42	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
43	My biggest concern for natural supports is their lake of training and no background screening. This is an extremely vulnerable population and are often taken advantage of.	Apr 19, 2011 7:16 AM

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

44	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
45	My natural supports often make me feel as though I don't need their help, when actually I do. I can use their help to give myself a small break every once in a while.	Apr 19, 2011 1:00 PM
46	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
47	My natura supports are very imited. My parents will not help at all, they feel that my childs disability is something he could "fix" if only he would try harder. My husbands mother helps occasionally but she is much older and truely 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
48	This is a very interesting topic, especially given the aging population. Sometimes the most reliable supports are ones the family has to pay for.	Apr 19, 2011 4:20 PM
49	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
50	Natural supports are busy with jobs, household tasks, personal lives and childcare of their children.	Apr 20, 2011 5:06 AM
51	Use a sibling for emergence only. try not to as she has already had to due without a lot just growing up in a family with a brother that is disabled.	Apr 20, 2011 8:15 AM
52	i can not stay alone all day by my self	Apr 20, 2011 9:14 AM
53	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
54	Natural supports cannot and should not take the place of permanent 24/7 support for my daughter. At some point, I will no longer be able to care for her and there will be no one else who can step in. She also deserves the opportunity to live as independently as possible, but will require support from quality staff to achieve that lifestyle.	Apr 20, 2011 7:15 PM
55	In real life for most people there really is no such thing as natural supports that are consistintly always available when you need them. It is hard to ask family for help if they are not offering help on their own.	Apr 21, 2011 11:43 AM

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56	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
57	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
58	most "natural Supports" are not qualified to care for our daughter.	Apr 22, 2011 12:29 AM
59	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
60	My older, nondisabled daughter, who lives with us, helps out occasionally, but not all that often. She has begun working in a full-time, professional career, and often brings work home with her at the end of a long day. In her free time, she sees her friends. I do 99 percent of all the caregiving which my disabled daughter needs. I am getting tired!	Apr 22, 2011 1:51 PM
61	People like to help other people, but don't realize how much we need, but their time/effort/support is not unlimited either. It is unrealistic for me to expect natural supports to make major changes in my two sons (with profound and difficult disabilities) lives.	Apr 22, 2011 8:52 PM
62	If and only if the person shared with is able to set good example of independence, self care, safety and health; perhaps with someone who needs help with finances and driving only.	Apr 23, 2011 1:27 AM
63	Our company provides services in two towns...one is small rural community, natural supports are greater here. In the larger city we have minor support and its from family.	Apr 25, 2011 9:12 AM