

# 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		80.2%	97
Parent/guardian of an individual(s) with a disability		14.9%	18
Caregiver of an individual(s) with a disability		2.5%	3
Individual with a Disability		2.5%	3
<b>answered question</b>			<b>121</b>
<b>skipped question</b>			<b>0</b>

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

		Response Percent	Response Count
0-4		3.3%	4
5-9		4.1%	5
10-14		14.0%	17
15-19		9.9%	12
19-24		27.3%	33
25+		41.3%	50
<b>answered question</b>			<b>121</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		52.1%	63
<b>Cognitive disability</b>		<b>84.3%</b>	<b>102</b>
Mental Health Disability		32.2%	39
Other (please specify)		27.3%	33
		<b>answered question</b>	<b>121</b>
		<b>skipped question</b>	<b>0</b>

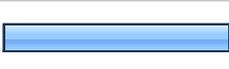
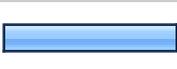
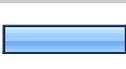
**4. Choose all that apply: I have "natural supports" that I can regularly depend on to help from the following:**

		Response Percent	Response Count
Immediate extended family (brothers, sisters, grandma, etc.)		0.0%	0
Neighbors		0.0%	0
Friends		0.8%	1
Church		0.8%	1
Social group		0.0%	0
<b>None that I can think of</b>		<b>92.6%</b>	<b>112</b>
Other (please specify)		13.2%	16
		<b>answered question</b>	<b>121</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
Little		0.0%	0
Miniscule		0.0%	0
<b>No support from "Natural supports"</b>		<b>100.0%</b>	<b>121</b>
<b>answered question</b>			<b>121</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>33.9%</b>	<b>41</b>
Sometimes		25.6%	31
Frequently		22.3%	27
A lot		18.2%	22
<b>answered question</b>			<b>121</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>77.7%</b>	<b>94</b>
I have received training and it has not been helpful		18.2%	22
I have received training and it has been somewhat helpful		2.5%	3
I have received training and it has been very helpful		1.7%	2
		<b>answered question</b>	<b>121</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>
	82
<b>answered question</b>	<b>82</b>
<b>skipped question</b>	<b>39</b>

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

1	Medical issues	Apr 13, 2011 8:20 PM
2	mute	Apr 13, 2011 8:37 PM
3	significant medical needs	Apr 13, 2011 10:13 PM
4	Autism Spectrum Disorder	Apr 14, 2011 8:41 AM
5	Blind, non-typical communication skills	Apr 14, 2011 11:41 AM
6	apraxia, sensory integration disorder	Apr 14, 2011 12:00 PM
7	Autism, severe behavioral challenges	Apr 15, 2011 7:27 AM
8	Autism	Apr 15, 2011 1:41 PM
9	autism	Apr 15, 2011 3:02 PM
10	Non-verbal Autistic	Apr 16, 2011 6:58 AM
11	seizures	Apr 16, 2011 8:39 AM
12	seizure disorder	Apr 17, 2011 8:53 AM
13	Cortically blind	Apr 18, 2011 6:32 AM
14	Asperger's	Apr 18, 2011 7:10 AM
15	autism	Apr 18, 2011 8:12 AM
16	Severe developmental delays, seizures,	Apr 18, 2011 8:39 AM
17	Autism with mental retardation	Apr 18, 2011 8:52 AM
18	developmental delay	Apr 18, 2011 9:56 AM
19	social, communication disability	Apr 18, 2011 9:59 AM
20	Diabetes	Apr 18, 2011 12:14 PM
21	Autism	Apr 19, 2011 5:27 AM
22	Autism, MR, anxiety disorder	Apr 19, 2011 6:24 AM
23	autism	Apr 19, 2011 9:46 AM
24	medically frail	Apr 20, 2011 9:54 AM
25	Epilepsy, OCD	Apr 20, 2011 10:21 AM
26	Rett Syndrome	Apr 20, 2011 12:03 PM
27	Learning Disabilities, Behavioral challenges	Apr 20, 2011 4:02 PM
28	seizure and bowel disorder (hirshbrungs)	Apr 21, 2011 7:28 AM
29	deve. delay and seizure disorder	Apr 21, 2011 8:01 AM

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

30	autism specturm disorder	Apr 21, 2011 1:46 PM
31	hearing, behavior, incontience	Apr 21, 2011 1:49 PM
32	Seizure disorder	Apr 21, 2011 3:00 PM
33	Autism, bipolar disorder	Apr 22, 2011 5:01 AM

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

1	One sibling, who has a full time job. He helps several hours in a month. Was sent out of the country last summer for his job.	Apr 13, 2011 10:01 PM
2	If I want to talk to my daughter's "natural support" person, I talk to myself.	Apr 14, 2011 8:41 AM
3	The only available to me is my husband/guardian	Apr 14, 2011 11:41 AM
4	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
5	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
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	none	Apr 15, 2011 8:17 AM
8	I have no natural supports.	Apr 15, 2011 3:02 PM
9	I never had an "natural supports" even from the beginning and felt it was an imposition to ever ask for help. I heard, "I raised mine, you raise yours" so I knew better than to ask. No one ever volunteered.	Apr 16, 2011 6:58 AM
10	We were able to hire our son's aide from school to help on occasion. 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
11	No natural supports. Due to level of medical needs, anyone spending time with our family member has to have plenty of training (ie: paid staff, plus mom)	Apr 17, 2011 7:18 PM
12	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
13	All my family live out of state, old parents 82 and 83, no family at all, neighbors even if I paid them they do not want to do it. Church they want I be at all the time with him, really hard even to go to church for the behavior issues. Friends same situation, they are scared to take care of him. . My brother live in other state, I do not have sister.	Apr 19, 2011 6:24 AM
14	Supported Living funded thru the Regional Center in California	Apr 19, 2011 5:44 PM
15	spouse	Apr 19, 2011 8:19 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	Natural supports are a fiction! Even in cases that claim to have used "natural supports" I have found the truth to be that those "n.s" were being paid or bartering for some quid pro quo. In my lengthy experience walking this path I have never seen true "natural supports". It does real harm to keep putting this out to the public as a solution to anything!	Apr 13, 2011 8:20 PM
2	They don't exist	Apr 13, 2011 8:25 PM
3	As the only parent providing support (physical, emotional, financial) for my child I also have to work full time, which limits the hours available for me to identify and develop natural supports. The "system" expects me to do this even though the "system" does not promote, locate, or train the public to see their role in the natural support process. Every time there's a gap in the service area, the "system" expects us to find and use "our natural supports" - even though they are nonexistent b	Apr 13, 2011 8:27 PM
4	we have no family in this state; the individual with the disability has no siblings; I've worked two jobs to keep the bills paid, so have no social supports	Apr 13, 2011 8:37 PM
5	Many people believe that since the disability happened in my family; it is up to my family to handle it. I think that is why there is such strong political support for "natural supports".	Apr 13, 2011 10:01 PM
6	I really haven't heard of natural supports before, though my parents may have (I'm guardian for my developmentally disabled sister who is very high needs with dual diagnosis and intense medical problems). Over the years, my parents have been told how my sister could do anything (be a nurse, have a driver's license, live on her own, etc.). They have been told that the community could help her achieve these goals. Ridiculous! She is a danger to herself and sometimes others, especially when her mental health issues spike. There are no "natural supports" available--she need intensive supervision and care from highly trained and well supported professionals. There's nothing "natural" about that. We cannot take care of my sister (even though we have lots of skills) and community supports are often non-existent or very sporadic at best. My sister has done well at Pueblo Regional Center for the past decade.	Apr 14, 2011 2:28 AM
7	When my mother was alive, she helped a great deal. Since her death, there is no one I can consistently count on for respite or help. Neighbors would help in an emergency but otherwise are too busy to help.	Apr 14, 2011 7:04 AM

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8	I have not been made to feel guilty because I follow every single "lead" someone gives me and then I report back . What they want to point to as a natural support is NOT Real, e.g. 100 miles away, no available staffing, don't work with adults w/autism, program underfunded. They say get your services through the waiver! Duh. Re: training? I know more about what is out there than the folks at APD who send email links to "check this out" like night classes at local schools, disability websites, job fairs etc. Nothing they send is helpful. e.g. a local CVS was partnering with APD to do a mentoring day. We went.....it was nice, tour and lunch. Afterwards I talked to the manager: guess what. No job carving available, all employees must be able to cash register, check id for cigarettes, beer, converse w/ customers who need assistance, etc. When I asked what supports would you provide.....he said.....what do you mean? I said well, training by another employee, work nearby to assist as needed. He said.....no way, we are staffed lean and mean. Anyone we hire has to come in and do the job 100%. Its pretty much sink or swim. Job mentoring.....looks good on paper. That's it.	Apr 14, 2011 8:41 AM
9	It's a nice concept, but not everyone has families who can or want to assist.	Apr 14, 2011 9:00 AM
10	We have only ourselves on which to rely to care for our DD son (21) and DD daughter (18) who require 24/7 oversight. We live in a rural area, and it is left to DH and myself unless we can privately pay for respite (residential) care. Since we are in our 70's and there are no family members willing to assist, we do not know what will happen when we can no longer care for them. Unfortunately, the money for the trust has been spent over the years for medical care, therapies, attempted remediation, etc.	Apr 14, 2011 10:08 AM
11	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
12	In Oklahoma Natural Supports is used as a weapon to hurt and restrict services. It was told to a family who provided support in their home of an adult child with significant disabilities and needed to obtain paid nursing to administer a shot to use a neighbor to give the shot. When the family said they don't know the neighbors they were expected to go introduce themselves for the sole purpose to have them give the injection.	Apr 14, 2011 11:41 AM
13	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
14	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
15	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
16	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

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17	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
18	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
19	Friends and neighbors are the best supports that you can think of. If they are willing to help out and understand the disability, life will be lot easier for the disabled and his/her parents/caregivers.	Apr 15, 2011 1:41 PM
20	I am a single parent with an adopted child. We have no family, I had to give up my career and work various parttime jobs to be available for my child who does not fit the day programs that are available. I do get Home Based funding which allows her to pay me for her training and assistance I give. Without that, I would have to put her into some form of housing(CILA) because I would have to make a living. I've lost my retirement security to keep her moving forward to being as independent as possible.	Apr 15, 2011 3:02 PM
21	Some of us don't have family to call upon, for many reasons. And I never wanted to burden my family members or "use them up"	Apr 15, 2011 5:10 PM
22	I was divorced soon after my son was diagnosed. I lived far from family and none would have assisted in any event...he was my "problem". I would go through as many as three day care providers a week when he was young just so I could work. I had to call in work due to lack of day care and had no idea when or if I would find another willing, paid, individual so I could work. I did not go out after work, had no social life, no community other than the people I worked with and needed to rush to get son from day care as soon as I got off work. I was often told that I needed someone special to help me or that I needed an expert to take care of my son before and after school. I received no child support as it was never inforced so poverty was just the way it was. I would skimp on food to pay day care so I could work. My parents, when alive, did not want me to move back the my home town because they did not want to be stuck caring for my son. No siblings nearby but they have their own families to care for at any rate. Folks with "problems" are avoided not embraced and that includes the families of disabled as well as the disabled themselves. That's reality.	Apr 16, 2011 6:58 AM
23	Nobody wants tohelp because the amount of work envolved with my child.	Apr 16, 2011 8:20 AM

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24	My husband is an only child and none of my 3 sybs live within 250 mi. I am a loving stepmom and we have no other children. Tony's biological mother sexually abused him so she is no help. My niece a young professional is designated successor guardian who is interested but lives 50 mi away and not readily available. Tony is in a CILA 200 miles from us because it was the only place we could find that gave him a room of his own and appeared well managed. We visit twice a month, but friends are not willing to make that trip. We want to set up a micro board, but have a problem finding members.	Apr 16, 2011 8:25 AM
25	I so wish I had natural supports, but when you have a family that walks away, you cannot force them or make them understand, I have fought this battle for over 30 years. It is very hard when you have no natural supports, but yourself, and because of this, caregivers are a MUST!!!! Taking care of an individual with so much need is almost impossible to do for one person, the stress is overwhelming. We too as parents need extreme help with individuals whose lives are medically and physically complicated. thank you.	Apr 16, 2011 8:39 AM
26	Natural supports will not work for my relative due to the level of severity and her living situation.	Apr 16, 2011 9:58 AM
27	more avenues to obtain support is desperately needed!!!! I NEED HELP!!!!	Apr 16, 2011 12:37 PM
28	The thing about natural supports, in my opinion, is that they should be an option that might be chosen, not the only possibility available, nor the way society expects us to get our needs met. A dependence on natural supports can lead to a feeling of dependence and too often the label of "burden." I remember when I was a child and my grandmother was quite old. She lived independently in her home, but was unable to maintain the home. She was preoccupied with "luring" people (relatives, friends, etc.) to her home and there was always a job to do. People came to feel used and avoided her. Now, as an adult with a husband and adult son who are dependent for all needs, a full time job, etc., I can become very overwhelmed and relate to my grandmother's predicament. I'd love some community support. When my husband first had his stroke, people came and visited, took him out for activities, helped with driving him to rehab, etc. Now, people have returned to their own busy lives. "Natural supports" can be very hard to sustain over a long period, particularly if there is no extended family. It is detrimental to relationships for one individual to provide natural supports out of a sense of guilt or duty. The charity model of care, which manifested in a loss of control and a dependence on the whims of others has been replaced with a consumer model, which empowers. Please, let's not go back.	Apr 16, 2011 1:41 PM
29	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
30	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
31	It is difficult to find someone to provide natural supports due to uncontrolled seizures. Most people are not comfortable.	Apr 17, 2011 8:53 AM
32	I agree with the theory of natural supports, but it doesn't pan out in reality.	Apr 17, 2011 4:33 PM

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33	Does the system request or require natural supports when an individual with ID is residing in a residential/group home? Parents of three biological adults with ID, MH, physical and behavioral issues. No natural supports, but lots of aggravation from the system!!	Apr 17, 2011 6:05 PM
34	No willing family in state. No neighbors that would be trusted with the responsibilities. As stated before, some medical and system requirements almost rule out "natural supports."	Apr 17, 2011 7:18 PM
35	Natural supports would be wonderful if everyone did not have their own life with no time to help .	Apr 18, 2011 6:26 AM
36	The natural support one would provide to an adult child (without a disability) is generally short term and emergent. Policy makers generally do not understand the amount of care and support our family members with a disability require and that it is inappropriate to ask 'friends' to assist when and if they have friend! Many counties in our state and the regional offices are trying to cut service by pushing the families to do needed care in lieu of paid staff!	Apr 18, 2011 6:32 AM
37	I have no family in my area except one daughter. Due to my youngest daughter's age (35) and multiple disabilities I cannot just leave her with someone like you were leaving a baby with a friend to run to the store. My oldest daughter works as a paid caregiver and there is always that fear that the state is going to say no, she can't get paid to do this work. She has to have a job as she is a single parent of three teenagers. She cannot do this work for free. And there is no one on the face of the earth that I trust my youngest daughter with as I do with my oldest daughter . This is my fear. If my oldest daughter is told she cannot work as paid staff she will not be available as natural staff as she will have to go find employment elsewhere.	Apr 18, 2011 6:35 AM
38	My parents have both passed away. When they were alive, they were very helpful. My husband's family is not supportive at all and my only sister lives 2000 miles away. In an extreme emergency I could call a neighbor or friend but would not do so unless it was a very real emergency.	Apr 18, 2011 6:39 AM
39	It's hard enough to get "natural support" when you have young, healthy, "normal" children. Who has the time or interest or patience or knowledge or strength to help adult children with problems? Not my relatives or friends.	Apr 18, 2011 7:10 AM
40	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 dont have the time, or they are afraid. Or any number of other reasons. So its all left to me and my husband. It has wrecked my health.	Apr 18, 2011 7:43 AM
41	My husband & I are the natural supports. I would love to have qualified people that could come in to support us in our caregiving. We do have a couple of respite providers that let us get out once in a while, but we pay out of pocket for them, as our daughter is on the EBD waiver & can only get respite in a nursing home setting & there are no real good choices for a nursing home setting to provide respite.	Apr 18, 2011 8:35 AM

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42	I have no one around to help with care for my disable son. he is dependent on my for everything from toileting to feeding him and dressing him. I am 70yrs and it is tough. He needs to be placed into a group home where he can get out into the community to do different things since I don't drive.	Apr 18, 2011 8:39 AM
43	Now in my mid 50's, my daughter in her late 20's, living in extreme rural America, caring for and losing my aging parents, no other siblings or close relatives to depend on, no immediate neighbors, no community services or respite services and the fact that the State is always looking for a way to cut support services to families with disabilities, our future is turning into a nightmare. There are no "natural supports" in our world and those who are supposed to be working as advocates to make life better for our young adults with disabilities seem to have lost their focus on helping the individual with disabilities. The policy makers spend all their energy on policies designed to tear the family unit apart, rather than assist the family unit in providing the best long term stable care for their child or loved one.	Apr 18, 2011 8:39 AM
44	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
45	I don't ask for help well. I am, also, a social worker, and I tend to offer help rather than take help. I have two adult sons with severe autism and a 22 year old son with Asperger's.	Apr 18, 2011 8:52 AM
46	Only "natural" supports in case of an extreme emergency. Day-to-day "natural" supports are not available.	Apr 18, 2011 9:09 AM
47	On occasion when I do need support there are none available. My children work and have their own lives to deal with, my husband has to work to support us and keep medical insurance to cover my illness. What you might consider natural supports are not always available. My husband is often sent out of state to work and I am left home alone for weeks at a time. My children live and work out of town also. Although I don't qualify for services, I'm stuck between a rock and a hard place.	Apr 18, 2011 12:14 PM
48	Im glad to share this info with someone other than my supposedly case manager yeah right.I have cp which causes me to require total physical assistance.Im a 29yr old caucasian female.I live alone.I do have a relationship with my father but its toxic.He's an alcoholic and verbal abusive towards me.Yet my case manager is telling me that i have to utilize him for natural supports.I pray that i dont loose my independence and the state force me back into a violital situation	Apr 18, 2011 12:16 PM
49	I've never had anyone ask or suggest natural supports.	Apr 18, 2011 12:59 PM
50	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
51	I do not have natural supports because my family members do not live close by and not able to drive to help me.	Apr 18, 2011 2:54 PM

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52	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
53	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
54	The only support I have is from my husband... the father of our son.. Other wise I have NONE... we do it all our selves and we are getting older....still on the waiting list.....	Apr 19, 2011 5:12 AM
55	"Natural Supports" is not an answer to the tremendous need for services for our children and young adults. Why not; we have had no training to find them, we do not have time in our days as most clients require 24/7 adult supervision, and there is no training for Natural Supports. Our children have complicated challenges.	Apr 19, 2011 5:18 AM
56	"natural supports" is just a catch phrase. Everyone appears to be able to tell me how to handle situations but never available or want to help	Apr 19, 2011 5:21 AM
57	"Natural supports" is nothing more than a concept to me and a convenient excuse for the state to deny services for adults.	Apr 19, 2011 5:27 AM
58	This what I going to mention is not a natural support but maybe could be a good support since the situation of the cut of budget, is only one community center that provide different type of activities but is to far away , is from the goverment, they have craft activities, outings, cooking class, for a minimum cost is similar to respite but they are many young adults and adults in that place at a minimum cost. The government should open different community center with the same concept in different areas of Orlando Florida. Will be more fun, more economic, able to socialise.	Apr 19, 2011 6:24 AM
59	My husband and I are my son's only natural support. My son is 36 years old, 6'3", 200 lbs., 24 hour total care. No one has ever "volunteered" to give us support. The only support we have ever had has been PAID support.	Apr 19, 2011 7:18 AM
60	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
61	We live in an area that we are not originally from so, we don't have natural supports in our area. Our extended family members live in another part of the state or out-of-state. Most of them have children and grandchildren of their own and were not able to assist with the care of our daughter even when we lived near by. I find that even the people who could help don't because of the level of need of the person with a disability.	Apr 19, 2011 8:27 AM

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

62	Natural supports are available to some but certainly not all disabled persons. If they have one person who is willing to be primary caregiver they are fortunate. If they have more than one they are the exception not the norm in my opinion.	Apr 19, 2011 10:57 AM
63	My husband and I cared for our daughter with autism until she was 27. She got up at 2am, so one of us had to get up too. We went on vacations to visit families by ourselves. We never ate out or went to a movie or event together. The stress was enormous. She had severe behavior problems that we couldn't handle. When she realized she was stronger than us, it was a problem.	Apr 19, 2011 11:28 AM
64	It is difficult to depend on others to help..They have their own interests and motivations that can conflict with ours. (my husband and myself) Everyone wants to get paid for helping...even "natural supports".	Apr 19, 2011 1:10 PM
65	They don't exist in small town and rural communities	Apr 19, 2011 1:29 PM
66	my son is almost 43 and has Down Syndrome. I'm a widow and feel lucky to have him around. I have made arrangements with a local organization to go into a host home situation when I die. He is pretty self-sufficient and self confident.	Apr 19, 2011 1:54 PM
67	We have no family in the area my son has many medical needs ie ventilator. Oxygen etc most people are not capable of taking care of him without medical training	Apr 20, 2011 9:54 AM
68	I have been so busy and consumed with other aspects, I have never thought much about specifically working on this area called natural supports. My husband and I have just done it ourselves until recently we have hired a DSW.	Apr 20, 2011 10:28 AM
69	My parents deceased,grandparents deceased,brothers deceased,live in rural area,church does not support, then state agency says until I am incompacitated or dead forget about getting any help for a total care person. She is 221/2 has no speech,no hand use,wheelchairbound,has to be turned,set up and etc. TOTAL CARE!!!! SHAME ON THE STATE OF OKLAHOMA that will not help support with tax dollars.Instead tax dollars go for the providers to pay outrageous prices for products that the regular guy does not have to pay.	Apr 20, 2011 12:03 PM
70	"natural supports" is fine, but should not be considered a replacement for the services that my child needs or may need in the future. expecting "natural supports" to provide these services when i do not have these "natural supports" is irrational. the services needed should be provided moreso because the "natural supports" are not available or attainable to me.	Apr 20, 2011 12:24 PM

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

71	<p>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.</p>	Apr 20, 2011 12:31 PM
72	N/A	Apr 21, 2011 7:28 AM
73	my parents are deceased and my hubands parents are elderly and cannot help.	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.**

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| 74 | The families I know who have benefitted from natural supports all have healthy family members living close to them. I have been envious of them over the years because we live near no family members. This has been one of my greatest heartaches. I worked hard to find paid support persons to help with my son when he was ages 2 - 15. He is now 22 and I am struggling to find any supports for him beyond his father and myself.   | Apr 21, 2011 1:46 PM |
| 75 | This is just not going to happen. We have no parents left, husband has one older sister, we are in our 60s. Never had much support at all.  | Apr 21, 2011 1:49 PM |
| 76 | 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 siblings 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. | Apr 21, 2011 2:26 PM |

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77	In reality, the only "natural supports" have been other parents with children/adults with disabilities who are also under incredible stress with the amount of caregiving necessary, but they are the ones who help.	Apr 21, 2011 3:00 PM
78	I do not support the idea that "natural supports" can or should assume the responsibilities of caring for an individual with disabilities, and all that is involved in that job	Apr 21, 2011 8:03 PM
79	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
80	Throughout the years tried to get help from natural supports and was told no. Offered to pay and still no.	Apr 22, 2011 8:28 AM
81	I am a 60 year old parent of an almost 26 year old son ith developmental disabilities. I am his primary caregiver, with absolutely zero "Natural Supports". My wife works 60 pus hours per wek at two diferent jobs to financialy support me and my son. He has had 17 different paid providers in the past seven years. The systems that exist for services are disfunctional, self serving, and a huge waste of money. I would rather have them pay me so I would be able to provide a stable, safe environment for my son.	Apr 22, 2011 10:19 AM
82	The idea of "natural supports" is great if you have accessability 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