

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		60.5%	101
Parent/guardian of an individual(s) with a disability		19.2%	32
Caregiver of an individual(s) with a disability		10.8%	18
Individual with a Disability		9.6%	16
		answered question	167
		skipped question	0

2. The individual with a disability is the following age		Response Percent	Response Count
0-4		0.0%	0
5-9		0.0%	0
10-14		0.0%	0
15-19		0.0%	0
19-24		0.0%	0
25+		100.0%	167
		answered question	167
		skipped question	0

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

		Response Percent	Response Count
Physical disability		53.9%	90
Cognitive disability		76.6%	128
Mental Health Disability		39.5%	66
Other (please specify)		24.6%	41
		answered question	167
		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.)		38.9%	65
Neighbors		11.4%	19
Friends		23.4%	39
Church		8.4%	14
Social group		4.8%	8
None that I can think of		41.9%	70
Other (please specify)		20.4%	34
		answered question	167
		skipped question	0

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

		Response Percent	Response Count
Strong		10.8%	18
Moderate		22.8%	38
Little		16.2%	27
Miniscule		20.4%	34
No support from "Natural supports"		29.9%	50
answered question			167
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		34.7%	58
Sometimes		41.9%	70
Frequently		13.8%	23
A lot		9.6%	16
answered question			167
skipped question			0

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

		Response Percent	Response Count
I have received no such training		67.1%	112
I have received training and it has not been helpful		16.2%	27
I have received training and it has been somewhat helpful		8.4%	14
I have received training and it has been very helpful		8.4%	14
		answered question	167
		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
	117
answered question	117
skipped question	50

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

1	Medical issues	Apr 13, 2011 8:20 PM
2	Neurological	Apr 13, 2011 8:27 PM
3	significant medical needs	Apr 13, 2011 10:13 PM
4	Type 1 Diabetes	Apr 13, 2011 10:23 PM
5	complex medical needs	Apr 13, 2011 10:45 PM
6	Autism Spectrum Disorder	Apr 14, 2011 8:41 AM
7	Difficult medical issues	Apr 14, 2011 9:16 AM
8	DS/ASD	Apr 14, 2011 11:30 AM
9	PDD Autism w/ explosive episode disorder	Apr 14, 2011 11:58 AM
10	Siezure Disorder	Apr 14, 2011 1:44 PM
11	Hearing impaired	Apr 14, 2011 3:58 PM
12	I have Pick's and am losing my mind	Apr 14, 2011 8:43 PM
13	deaf	Apr 15, 2011 5:25 PM
14	Non-verbal Autistic	Apr 16, 2011 6:58 AM
15	seizures	Apr 16, 2011 8:39 AM
16	Brain injury	Apr 16, 2011 6:37 PM
17	visually impaired	Apr 16, 2011 8:15 PM
18	deafblind,cerebral palsy-tactile sign and read/write Braille	Apr 17, 2011 5:20 AM
19	mild cognitive and mental health disabilities and other health	Apr 17, 2011 8:32 AM
20	minimal brain damage due to abnormal chromosome along with non verbal learning disability	Apr 17, 2011 10:50 PM
21	Cortically blind	Apr 18, 2011 6:32 AM
22	Asperger's	Apr 18, 2011 7:10 AM
23	Severe Downs Syndrome	Apr 18, 2011 7:33 AM
24	Severe developmental delays, seizures,	Apr 18, 2011 8:39 AM
25	Autism with mental retardation	Apr 18, 2011 8:52 AM
26	Diabetes	Apr 18, 2011 12:14 PM
27	some behavioral problems-temper tantrums	Apr 18, 2011 12:57 PM
28	Autism Spectrum Disorder -low functioning/MR/Epilepsy	Apr 18, 2011 1:30 PM

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

29	Special Health Care Needs also	Apr 18, 2011 3:33 PM
30	Cancer	Apr 19, 2011 5:55 AM
31	Autism, MR, anxiety disorder	Apr 19, 2011 6:24 AM
32	autism	Apr 19, 2011 9:46 AM
33	Behavioral	Apr 19, 2011 1:14 PM
34	visual	Apr 19, 2011 6:30 PM
35	Uncontrolled seizures	Apr 19, 2011 10:03 PM
36	Epilepsy, OCD	Apr 20, 2011 10:21 AM
37	Learning Disabilities, Behavioral challenges	Apr 20, 2011 4:02 PM
38	hearing, behavior, incontience	Apr 21, 2011 1:49 PM
39	Seizure disorder	Apr 21, 2011 3:00 PM
40	medically fragile, chronic lung disease	Apr 22, 2011 12:29 AM
41	develoamental disability	Apr 25, 2011 9:12 AM

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

1	ex-husband	Apr 13, 2011 8:24 PM
2	family	Apr 14, 2011 6:43 AM
3	If I want to talk to my daughter's "natural support" person, I talk to myself.	Apr 14, 2011 8:41 AM
4	Friends of the person with the disability from a group of typical persons he is part of	Apr 14, 2011 8:43 AM
5	minimal family support	Apr 14, 2011 8:44 AM
6	While there are some more temporary people in his life, there is no one who I can depend on regularly. Not even family.	Apr 14, 2011 9:08 AM
7	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
8	I live alone so I really don't have anyone to become a caregiver	Apr 14, 2011 8:43 PM
9	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
10	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
11	my son resides in a group home, i am still involved in the crisis that occur	Apr 16, 2011 7:37 AM
12	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
13	synagogue	Apr 17, 2011 5:20 AM
14	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
15	I'm in a circle group	Apr 17, 2011 10:50 PM
16	Our Daughter	Apr 18, 2011 8:21 AM
17	Son's dad who is a co-guardian	Apr 18, 2011 10:45 AM
18	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
19	we have family and friends supports but cannot rely on them "regularly", only occasionally.	Apr 18, 2011 12:57 PM
20	natural supports would be me, my child's mother. However, I am single, work more than full time as a professor and have no family/friends local that can support. Severity of daughter's problems do not lend themselves to natural support help. My daughter's father lives 5 miles away and works.	Apr 18, 2011 1:30 PM

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

21	A few now and then but not regularly available to fill in when his occasional staff is not available.	Apr 18, 2011 2:18 PM
22	Parent to Parent families	Apr 18, 2011 3:33 PM
23	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 scare to take care of him. . My brother live in other state, I do not have sister.	Apr 19, 2011 6:24 AM
24	coworkers	Apr 19, 2011 6:32 AM
25	Occasionally if there is a funeral or wedding my friend will help out otherwise its up to our immediate family to provide continual care.	Apr 19, 2011 6:37 AM
26	I have 2 people who will help, not regularly, and they are in their seventies.	Apr 19, 2011 9:02 AM
27	Only have siblings as both parents are deceased and all siblings care for youngest who is disabled	Apr 19, 2011 1:14 PM
28	Supported Living funded thur the Regional Center in California	Apr 19, 2011 5:44 PM
29	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
30	my mom but she works and has been sick	Apr 20, 2011 9:14 AM
31	NAMI	Apr 20, 2011 9:44 AM
32	very limited. other people help but don't understand all the time needed	Apr 21, 2011 12:45 PM
33	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
34	disability community	Apr 23, 2011 12:30 PM

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	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
3	We are the natural supports and the necessity is lifelong. There are more and more needs with the the degree and complexity of an individuals disability. Most people that push natural supports have never walked in our shoes, and yes it is the easy answer to budget issues. One of the worst parts is that we have to keep educating the world that this doesn't just last a week, month, or years but a lifetime and it gets even more difficult when a person reaches 21.	Apr 13, 2011 8:27 PM
4	We have no extended family. The only natural support for our daughter is her brother, who lives out-of-state and can assist only very occasionally. Aside from that, our daughter's physical needs are so intensive that there are no friends, social groups, churches, volunteers, etc. who are both willing and competent to take them on. All the people who provide care for our daughter, with the exception of us (the parents), are paid. I have heard many parents of children with DD express how disappointed they are that everyone in their child's life is paid to be there.	Apr 13, 2011 8:38 PM
5	I am a part-time caregiver for my adult son with severe physical disabilities and a full time caregiver for my husband who became a hemiplegic and intellectually disabled after a severe stroke. Prior to his illness, we had many friends here in Denver and family that called despite being out-of-town. When he had the stroke, many people expressed concern and helped, but that was four years ago and now we literally NEVER have people come and visit him, take him out to Starbucks (he drools and constantly coughs so not socially acceptable) or whatever. I also have a full time job, which I now do at home, but I am so overwhelmed. My health is failing and I can no longer sleep well for worrying. Natural supports are what you have when it is easy to support you. Once it's hard, the truth is that it's natural to resume you own busy life and better to be occasionally guilty than take on something that's esthetically, physically, and emotionally difficult. I do understand that it's hard to support someone longterm. Some folks may have endless "natural supports," but my experience is that people can not sustain extraordinary, unending assistance.	Apr 13, 2011 9:26 PM
6	Natural supports is another term for free help. Not many people with time nor the talent to help with my child.	Apr 13, 2011 9:29 PM
7	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
8	I am fortunate to have adult children and friends who can support us in a crisis. My oldest son is always available to help. HOWEVER, I don't, won't and can't expect my adult children and friends to provide the day-to-day support needed. They have their own families, responsibilities, jobs, etc. and shouldn't be expected to make-up for insufficient service system supports - even though they do . . . and so do I.	Apr 13, 2011 10:45 PM

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9	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
10	I had this in new york	Apr 14, 2011 6:43 AM
11	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
12	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
13	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
14	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
15	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
16	I have found the development of natural supports to take a long time, to involve some "starts, stops, backing up and starting over," to be absolutely essential to avoid my own burnout. I have also found that I have had to take care not to burnout people who are natural supports and to ensure they know how crucial they are to creating a good life for my son.	Apr 14, 2011 8:43 AM

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17	sucks when you are seeking services from an agency and they tell you to use your family.	Apr 14, 2011 8:44 AM
18	I believe the system is kidding itself if it thinks that we could actually find people who would have this kind of commitment to adult children. The world is too busy. People have to work. It is a lot to ask people to help. At "best" we "might" be able to get people to be there in an emergency situation only. Natural supports are a farce.	Apr 14, 2011 9:08 AM
19	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
20	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
21	1. Family is widely disbursed. 2. Community is 'friendly' but doesn't offer support. 3. We are old and tired and to search for people willing to 'offer' requires us to 'ask'.	Apr 14, 2011 11:30 AM
22	Since few of us live in rural communities and extended families are usually spread across state lines, it is difficult to find natural supports. Also as our children age so do we, and one day we will be gone. Then what supports will they have. FL provides very little help with any kind of decent services for the disabled, so parents are usually the only support.	Apr 14, 2011 11:58 AM
23	It would be nice if my daughter had friends and not just family	Apr 14, 2011 1:44 PM
24	Natural Supports is great for those who have that available, but in our case we don't. Plus my son has behavioral issues in addition to his cognitive deficits which makes him difficult to watch. His brother no longer will watch him because of his behaviors.	Apr 14, 2011 3:58 PM
25	I have no other family members to help out. Community members and neighbors may offer help, but it usually is not when and how I need help. Many times, I have found when I do try to use a community member to help it turns into more work for me---for example, I have to provide the transportation for my adult child to someplace I would not normally go to; this takes my time and money for gas. For example, there are groups that offer dances or other social activities for people with disabilities, but again, I have to provide the transportation and then I wait in the car until it is over. Often the times of these kind of activities conflict with my other commitments, so my adult child can't participate in them.	Apr 14, 2011 7:05 PM
26	for me before I reach the point I will need help I have made my plans terminate so I won't need a caregiver	Apr 14, 2011 8:43 PM
27	Close friends and family do come through in a pinch but there are no regular natural supports in our life for our son.	Apr 14, 2011 11:34 PM
28	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

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29	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
30	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
31	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
32	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
33	Very important for social relations and going out. At home it's always more easy !!	Apr 16, 2011 12:49 AM
34	The support is recent, and follows years of terrible disappointment from hoping to get natural supports from family.	Apr 16, 2011 6:20 AM
35	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 enforced 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 to 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
36	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

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

37	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
38	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
39	Natural supports will not work for my relative due to the level of severity and her living situation.	Apr 16, 2011 9:58 AM
40	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
41	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
42	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

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43	Natural support is a great idea if it is available. I support individuals from the institutions in KY. The community does not accept them as their own and they do have struggles while transitioning! Most of them do not even have family that want to be involved!	Apr 16, 2011 6:37 PM
44	Care providers are threatened by these supports.	Apr 16, 2011 8:15 PM
45	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
46	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
47	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
48	My family members who support me emotionally and with advice are aging. I don't want to burden the next generation.	Apr 17, 2011 8:04 AM
49	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/brag 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
50	Natural supports seem to be more available when your children are young. As they age their disabilities become more complex. Friends and family members may not be equipped mentally and physically to deal with these complexities. As parents and guardians age their needs may become such that they need help and support. Siblings go on to have their own families or move away and are not always available to provide care. Parents have enough stress to deal with, without having to recruit and train others. What happens when the parents die? Who gets stuck with the responsibilities then?????	Apr 17, 2011 3:32 PM
51	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

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52	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
53	i'm interested in doing public speaking	Apr 17, 2011 10:50 PM
54	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
55	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
56	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
57	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
58	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
59	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 to 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 are trying to explain to them, so usually I struggle with it myself.	Apr 18, 2011 7:35 AM
60	When I'm gone, MANY other people will care enough to watch... People who love him for who he is.	Apr 18, 2011 7:35 AM
61	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

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

62	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
63	I have no one around to help with care for my disabled son. He is dependent on me for everything from toileting to feeding him and dressing him. I am 70 years 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
64	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
65	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
66	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
67	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
68	I feel like I can rely on support from friends for simple tasks, but not for anything major.	Apr 18, 2011 11:08 AM
69	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
70	I'm 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. I'm a 29 year old Caucasian female. I live alone. I do have a relationship with my father but it's toxic. He's an alcoholic and verbally abusive towards me. Yet my case manager is telling me that I have to utilize him for natural supports. I pray that I don't lose my independence and the state force me back into a violent situation.	Apr 18, 2011 12:16 PM

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71	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
72	My daughter's disabilities are such that I am not comfortable with natural supports caring for her. My child needs a personal care attendant when I am not available to care for her. My job supports us though and that must be prioritized. Therefore, my child needs a personal care attendant.	Apr 18, 2011 1:30 PM
73	Because he has behavioral issues, it is difficult to find others who are willing to assist. He seldom has consistent staffing.	Apr 18, 2011 2:18 PM
74	Family too busy	Apr 18, 2011 3:02 PM
75	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
76	I provide care for a young lady with MR and Bipolar Disorder. She has a very hard time making and keeping friends due to her disability. She was doing better with behavior and mental health services but her services have been cut in half. She is now in teir 4 and has lost her dental and mental health. She has to decide between having a companion and getting behavior services. She has a little of both but it is not enough. I feel sad for her because she has so much potential. Her mother was a drug user and that probably caused her disability. This young lady has been let down her entire life. She has no family or real friends and depends on paid supports.	Apr 19, 2011 1:15 AM
77	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
78	"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
79	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
80	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

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81	When our child with a disability was young Grandparents may assist if asked but only if we asked and only if it was an emergency. Very gratefully, my Mother did one weekend a year came over 2 nights so we could go away for a long weekend away and that was so appreciated. My two sister in laws and niece helped when they could but they had children to care for and they work so their time was limited but in emergencies they were there. Now my adult child has no Grandmom, my sister in laws are not able to help and unless my 40 year old son can assist we have no natural support - he has a family and we only ask him in emergency situations. We hear people retirement can go on extended vacations or even out for a day and just get in the car and go with no plans or destination in mind - we would pray for the day that we could enjoy a peaceful time away together for a brief respite so that we can come back strong to continue to care for our adult child who we love dearly.	Apr 19, 2011 6:37 AM
82	My biggest concern for natural supports is their lack of training and no background screening. This is an extremely vulnerable population and are often taken advantage of.	Apr 19, 2011 7:16 AM
83	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
84	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
85	With certain disabilities it is overwhelming to a "natural support" person to look at all of the possible issues and be prepared. The idea that all persons with disabilities will be "easy" enough to be supported by free help is just another attempt at cookie cutter approach to dealing with persons with disabilities.	Apr 19, 2011 9:02 AM
86	Each situation is different--one size does not fit all. As a parent, I respect those who can/are willing to provide 24 hr. care for their family member; however, I also respect those who are unable to do the same, for various reasons. I also think it's unfair for people/parents/professionals to judge others and force their opinion on everyone, just because they either are able themselves to depend on natural supports and are successful at providing 24 hr. care or they expect natural supports to do so. I believe the underlying motive (not of parents) of this belief is for funding reasons only. I think the best for many individuals is to be cared for by their family; however, I don't see that as a true option for many families. My real focus is to improve the direct care staff that provide care for people with disabilities. It seems like the low pay attracts the most undesirable people to apply for this work. Our most vulnerable people in our society, people with disabilities, those who are elderly, and our young children, deserve better quality care than most are receiving.	Apr 19, 2011 10:06 AM
87	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

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88	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
89	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
90	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
91	They don't exist in small town and rural communities	Apr 19, 2011 1:29 PM
92	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
93	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
94	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
95	Natural supports are busy with jobs, household tasks, personal lives and childcare of their children.	Apr 20, 2011 5:06 AM
96	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
97	i can not stay alone all day by my self	Apr 20, 2011 9:14 AM
98	NAMI - National Alliance on Mental Illness - saved my life. I am a spouse (Not a choice above), I have a support group, incredibly valuable education and caregiving assistance. all from NAMI - no one else ever helped me.	Apr 20, 2011 9:44 AM
99	families will and/or SHOULD take care of their own	Apr 20, 2011 1:27 PM
100	natural supports are not as special as you are trying to make them alot of them only want to keep the person, client, person with disabilities.....around only for there check	Apr 21, 2011 6:18 AM

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101	The only natural reliable support that my daughter has is me. She has four brothers, three of whom live in the same town as she and I do. Her four brothers have wives, children, school, church, work, and community obligations and are not available to "help" me with my daughter's care. I have provided her care prior to the waiver, during the waiver, and often even now that I am over the magic age of 70. When a paid caregiver does not show up to care for my daughter, her care falls on me. I recently has major surgery and still there is no continuity to her care. I wonder what happens when I die?	Apr 21, 2011 9:42 AM
102	In real life for most people there really is no such thing as natural supports that are consistently 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
103	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
104	sometimes if you have an individual who is independent, people think you don't need support. but you need support the same as others.	Apr 21, 2011 12:45 PM
105	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
106	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
107	Natural supports is wonderful for the very few who have this in place. My situation is dire. I cannot find and/or keep a job as I have NO ONE to care for my two adopted sons. Their father rarely takes them to give me a weekend break. I often refer to myself as 'handicapped by proxy' as I am stuck with a small window of opportunity to hold a job---a window so small and with so many exclusions (kid is sick, ice/snow, no transportation or workshop due to holiday, etc.) that I am not even considered for the job should I even get to the interview stage. I suffer from hypertension, am pre-diabetic and have depression and anxiety. I also have bad joints and pain from arthritis. I am only 54, sometimes feel like I am 90. I worry about what would happen should I get sick. People in my situation need HELP, The lawmakers need to understand this.	Apr 21, 2011 5:04 PM
108	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
109	most "natural Supports" are not qualified to care for our daughter.	Apr 22, 2011 12:29 AM
110	Natural supports are so limited---limited to a few well meaning relatives without the time to really make any difference regarding real caregiving. Without pay and /or a calling for service work, it's hard to live the 'double life' caregiving requires you to do.	Apr 22, 2011 12:46 AM

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111	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
112	I do not use 'natural supports' for my adult child. It has been my experience that such support is none existent or at least very infrequent and haphazard. Friends who have relied on such supports have been deeply disappointed in the support provided.	Apr 22, 2011 2:04 PM
113	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
114	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
115	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
116	Careing for my child in her younger years was so intensive that my husband and I lost contaact with our church, most family, & friends.Our ability to start new relationship was limited to families of other disabled children and the professionals who support them. Currently to support our daughter a caretaker must have specialized training. It is not realistic to use natural supports except on a very limited scale.	Apr 25, 2011 6:59 AM
117	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