


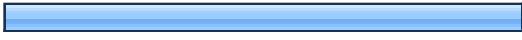


# Are There Really "Natural Supports" for Individuals with Disabilities?










1. I am a		Response Percent	Response Count
Parent/guardian and caregiver of an individual(s) with a disability		76.8%	377
Parent/guardian of an individual(s) with a disability		14.7%	72
Caregiver of an individual(s) with a disability		4.5%	22
Individual with a Disability		4.1%	20
		<b>answered question</b>	<b>491</b>
		<b>skipped question</b>	<b>0</b>

2. The individual with a disability is the following age		Response Percent	Response Count
0-4		4.7%	23
5-9		12.6%	62
10-14		15.5%	76
15-19		13.2%	65
19-24		20.0%	98
25+		34.0%	167
		<b>answered question</b>	<b>491</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		47.9%	235
<b>Cognitive disability</b>		<b>77.8%</b>	<b>382</b>
Mental Health Disability		33.4%	164
Other (please specify)		28.5%	140
		<b>answered question</b>	<b>491</b>
		<b>skipped question</b>	<b>0</b>

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

		Response Percent	Response Count
<b>Immediate extended family (brothers, sisters, grandma, etc.)</b>		<b>41.5%</b>	<b>204</b>
Neighbors		9.2%	45
Friends		24.2%	119
Church		12.8%	63
Social group		7.7%	38
None that I can think of		37.9%	186
Other (please specify)		17.7%	87
		<b>answered question</b>	<b>491</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		12.0%	59
Moderate		22.0%	108
Little		21.8%	107
Miniscule		19.6%	96
<b>No support from "Natural supports"</b>		<b>24.6%</b>	<b>121</b>
<b>answered question</b>			<b>491</b>
<b>skipped question</b>			<b>0</b>

6. I have been made to feel "guilty" by other parents, professionals, service folks, articles in magazines/bulletins, the "system," and/or others regarding my level of having "natural supports"

		Response Percent	Response Count
Never		37.5%	184
<b>Sometimes</b>		<b>39.7%</b>	<b>195</b>
Frequently		14.7%	72
A lot		8.1%	40
<b>answered question</b>			<b>491</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>71.3%</b>	<b>350</b>
I have received training and it has not been helpful		12.6%	62
I have received training and it has been somewhat helpful		11.2%	55
I have received training and it has been very helpful		4.9%	24
		<b>answered question</b>	<b>491</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>
	304
<b>answered question</b>	<b>304</b>
<b>skipped question</b>	<b>187</b>

**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	mute	Apr 13, 2011 8:37 PM
4	significant medical needs	Apr 13, 2011 10:13 PM
5	Type 1 Diabetes	Apr 13, 2011 10:23 PM
6	complex medical needs	Apr 13, 2011 10:45 PM
7	non-verbal	Apr 13, 2011 10:56 PM
8	intractable epilepsy and autism	Apr 14, 2011 7:46 AM
9	Autism Spectrum Disorder	Apr 14, 2011 8:41 AM
10	Difficult medical issues	Apr 14, 2011 9:16 AM
11	Behaviors with Agression, due to sever Autism	Apr 14, 2011 10:26 AM
12	Asperger's	Apr 14, 2011 11:13 AM
13	DS/ASD	Apr 14, 2011 11:30 AM
14	Blind, non-typical communication skills	Apr 14, 2011 11:41 AM
15	PDD Autism w/ explosive episode disorder	Apr 14, 2011 11:58 AM
16	apraxia, sensory integration disorder	Apr 14, 2011 12:00 PM
17	autism	Apr 14, 2011 12:08 PM
18	developmental disability-Autism	Apr 14, 2011 12:29 PM
19	Siezure Disorder	Apr 14, 2011 1:44 PM
20	Traumatic Brain Injury	Apr 14, 2011 3:27 PM
21	Speech impairment (nonverbal)	Apr 14, 2011 3:33 PM
22	Non Verbal, and uses a wheelchair	Apr 14, 2011 3:37 PM
23	Hearing impaired	Apr 14, 2011 3:58 PM
24	Multiple	Apr 14, 2011 4:55 PM
25	seizures	Apr 14, 2011 6:17 PM
26	I have Pick's and am losing my mind	Apr 14, 2011 8:43 PM
27	Developmental Disability: Autism	Apr 15, 2011 6:16 AM
28	Autism, severe behavioral challenges	Apr 15, 2011 7:27 AM
29	diagnosis of Down syndrome	Apr 15, 2011 8:46 AM

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

30	Developmental disability	Apr 15, 2011 10:05 AM
31	Autism	Apr 15, 2011 1:41 PM
32	autism	Apr 15, 2011 3:02 PM
33	autism, i don't consider it mental health	Apr 15, 2011 3:14 PM
34	PDD-NOS, ASD	Apr 15, 2011 3:52 PM
35	deaf	Apr 15, 2011 5:25 PM
36	non verbal	Apr 15, 2011 6:45 PM
37	XXYY which affects him socially, intellectually, physically	Apr 16, 2011 6:05 AM
38	Non-verbal Autistic	Apr 16, 2011 6:58 AM
39	profound hearing loss	Apr 16, 2011 7:07 AM
40	seizures	Apr 16, 2011 8:39 AM
41	autism, among other issues	Apr 16, 2011 12:49 PM
42	Brain injury	Apr 16, 2011 6:37 PM
43	visually impaired	Apr 16, 2011 8:15 PM
44	seizures	Apr 17, 2011 2:14 AM
45	deafblind,cerebral palsy-tactile sign and read/write Braille	Apr 17, 2011 5:20 AM
46	autism	Apr 17, 2011 8:02 AM
47	mild cognitive and mental health disabilities and other health	Apr 17, 2011 8:32 AM
48	seizure disorder	Apr 17, 2011 8:53 AM
49	Epilepsy, Lennox-Gaustat Syndrome	Apr 17, 2011 10:58 AM
50	autism	Apr 17, 2011 2:57 PM
51	Autism. Hearing loss	Apr 17, 2011 9:36 PM
52	minimal brain damage due to abnormal chromosome along with non verbal learning disability	Apr 17, 2011 10:50 PM
53	Cortically blind	Apr 18, 2011 6:32 AM
54	Asperger's	Apr 18, 2011 7:10 AM
55	social skills issues as well as behavioral.	Apr 18, 2011 7:16 AM
56	Global developmental delay (all in all)	Apr 18, 2011 7:21 AM
57	Severe Downs Syndrome	Apr 18, 2011 7:33 AM

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

58	autism	Apr 18, 2011 7:45 AM
59	Down Syndrome, both mental and physical	Apr 18, 2011 8:01 AM
60	autism	Apr 18, 2011 8:08 AM
61	autism	Apr 18, 2011 8:12 AM
62	Severe developmental delays, seizures,	Apr 18, 2011 8:39 AM
63	Autism with mental retardation	Apr 18, 2011 8:52 AM
64	Progressive/terminal neuromuscular disease	Apr 18, 2011 8:58 AM
65	Autism	Apr 18, 2011 9:20 AM
66	Autism- a Developmental Disability	Apr 18, 2011 9:22 AM
67	Mood, severe ADHD, speech/language deficits	Apr 18, 2011 9:24 AM
68	developmental delay	Apr 18, 2011 9:56 AM
69	social, communication disability	Apr 18, 2011 9:59 AM
70	severe anaphylactic food allergies	Apr 18, 2011 10:02 AM
71	Medical Disabilities including heart defect and sleep apnea which cannot be treated.	Apr 18, 2011 10:45 AM
72	SLI	Apr 18, 2011 10:47 AM
73	Autism Spectrum Disorder (PDD-NOS), Learning Disability	Apr 18, 2011 11:41 AM
74	Diabetes	Apr 18, 2011 12:14 PM
75	some behavioral problems-temper tantrums	Apr 18, 2011 12:57 PM
76	Down Syndrome	Apr 18, 2011 1:24 PM
77	Autism Spectrum Disorder -low functioning/MR/Epilepsy	Apr 18, 2011 1:30 PM
78	emotional	Apr 18, 2011 1:59 PM
79	Autism, ADHD, Manic/ Depressive, OCD	Apr 18, 2011 2:07 PM
80	Autism, Down syndrome, amputee and medically fragile	Apr 18, 2011 2:47 PM
81	Special Health Care Needs also	Apr 18, 2011 3:33 PM
82	autism	Apr 18, 2011 3:42 PM
83	ADHA	Apr 18, 2011 5:43 PM
84	Fragile X Syndrome	Apr 18, 2011 6:44 PM
85	Autism	Apr 18, 2011 8:16 PM

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

86	autism spectrum and muscular dystrophy	Apr 18, 2011 8:20 PM
87	hearing	Apr 18, 2011 8:47 PM
88	vision impairment	Apr 18, 2011 9:25 PM
89	specific learning disability	Apr 18, 2011 9:49 PM
90	xxy syndrome, symptoms are severe speech difficulties, slight gross and fine motor difficulties, auditory memory problems.	Apr 19, 2011 4:04 AM
91	Visual Impairment, Epilepsy	Apr 19, 2011 4:08 AM
92	Autism	Apr 19, 2011 5:27 AM
93	Cancer	Apr 19, 2011 5:55 AM
94	Autism, MR, anxiety disorder	Apr 19, 2011 6:24 AM
95	autism	Apr 19, 2011 9:46 AM
96	Health Disability	Apr 19, 2011 9:50 AM
97	Autism	Apr 19, 2011 9:54 AM
98	Aspergers Disorder	Apr 19, 2011 10:28 AM
99	Developmental Disability - Autism	Apr 19, 2011 11:16 AM
100	Rubinstein-Taybi syndrome	Apr 19, 2011 11:49 AM
101	Behavioral	Apr 19, 2011 1:14 PM
102	Developmental disability	Apr 19, 2011 1:31 PM
103	Autism	Apr 19, 2011 2:01 PM
104	Suppressed immune system	Apr 19, 2011 3:23 PM
105	Down Syndrome	Apr 19, 2011 3:24 PM
106	Autism	Apr 19, 2011 3:27 PM
107	autism	Apr 19, 2011 4:11 PM
108	autism	Apr 19, 2011 6:11 PM
109	visual	Apr 19, 2011 6:30 PM
110	autism	Apr 19, 2011 7:34 PM
111	special health care needs	Apr 19, 2011 9:42 PM
112	Uncontrolled seizures	Apr 19, 2011 10:03 PM
113	blind	Apr 20, 2011 8:24 AM



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

114	Profoundly hearing impaired	Apr 20, 2011 9:40 AM
115	medically frail	Apr 20, 2011 9:54 AM
116	I have two adopted children with severe disabilities	Apr 20, 2011 9:56 AM
117	Epilepsy, OCD	Apr 20, 2011 10:21 AM
118	Rett Syndrome	Apr 20, 2011 12:03 PM
119	Learning Disabilities, Behavioral challenges	Apr 20, 2011 4:02 PM
120	seizure and bowl disorder (hirshbrungs)	Apr 21, 2011 7:28 AM
121	deve. delay and seizure disorder	Apr 21, 2011 8:01 AM
122	Behavioral	Apr 21, 2011 8:11 AM
123	speech/communication	Apr 21, 2011 12:53 PM
124	Autism	Apr 21, 2011 1:39 PM
125	autism specturm disorder	Apr 21, 2011 1:46 PM
126	hearing, behavior, incontience	Apr 21, 2011 1:49 PM
127	Seizure disorder	Apr 21, 2011 3:00 PM
128	Autism	Apr 21, 2011 5:30 PM
129	Autism, Tuberous Sclerosis	Apr 21, 2011 6:23 PM
130	Autism	Apr 21, 2011 6:32 PM
131	severe sensory issues	Apr 21, 2011 7:36 PM
132	vision, endocrine, more	Apr 21, 2011 9:37 PM
133	medically fragile, chronic lung disease	Apr 22, 2011 12:29 AM
134	Autism, bipolar disorder	Apr 22, 2011 5:01 AM
135	seizure disorder	Apr 22, 2011 11:42 AM
136	at the momement, she seems to have an undiagnosed depression.	Apr 22, 2011 1:51 PM
137	autism	Apr 22, 2011 8:52 PM
138	PDD-NOS	Apr 23, 2011 8:23 AM
139	developmental disability	Apr 25, 2011 9:12 AM
140	developmental Autism	Apr 25, 2011 10:34 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	Friends from child's school	Apr 13, 2011 9:56 PM
3	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
4	People offer, but after a while, unless they have personal experience, they drop away. They expect "progress" and don't see any.	Apr 13, 2011 10:51 PM
5	When I say immediate. There is only one person besides myself that can dependably help me care for my child.	Apr 13, 2011 10:56 PM
6	family	Apr 14, 2011 6:43 AM
7	rarely, my sister	Apr 14, 2011 7:46 AM
8	If I want to talk to my daughter's "natural support" person, I talk to myself.	Apr 14, 2011 8:41 AM
9	Friends of the person with the disability from a group of typical persons he is part of	Apr 14, 2011 8:43 AM
10	minimal family support	Apr 14, 2011 8:44 AM
11	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
12	My immediate Family consists of myself a 49 year old, 5'2', single mom; my 20 year old son that is busy with school and his social life; and my 54 year old sister. Both my parents are dead. My exhusband, the father of my children is long gone and I don't even know where he lives, somewhere maybe in California. He stopped sending child support at least 5 years ago, and before that it was irregular. He stopped taking his son for an occasional visit on a weekend at least 7 years ago when his girlfriend refused to allow my son in her home stating that he was uncontrollable like an animal.	Apr 14, 2011 10:26 AM
13	Now--spouse. 10 years ago, none	Apr 14, 2011 11:13 AM
14	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
15	The only available to me is my husband/guardian	Apr 14, 2011 11:41 AM
16	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
17	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
18	Local support group	Apr 14, 2011 3:33 PM
19	We have a school aide that we can use occasionally.	Apr 14, 2011 3:37 PM
20	Co-workers	Apr 14, 2011 4:55 PM

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

21	We have a couple of people who I feel we could call but on an ongoing basis I would have to say we DO NOT have "natural supports."	Apr 14, 2011 5:09 PM
22	People I pay to support me.	Apr 14, 2011 8:03 PM
23	I live alone so I really don't have anyone to become a caregiver	Apr 14, 2011 8:43 PM
24	I have family but I can't regularly depend on them	Apr 14, 2011 9:29 PM
25	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
26	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
27	respite care workers	Apr 15, 2011 7:51 AM
28	none	Apr 15, 2011 8:17 AM
29	Occasional financial help with medical bills from my sister. Otherwise, I don't know what "natural supports" means. But I don't have any family, neighbors, or friends etc. that can help us out on regular basis.	Apr 15, 2011 8:46 AM
30	I have no natural supports.	Apr 15, 2011 3:02 PM
31	definition of natural supports would be great at the beginning of the survey. my answer is in regards to "regularly depend on". we do get free respite from a non profit group monthly but not sure if it qualifies.	Apr 15, 2011 3:14 PM
32	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
33	my son resides in a group home, i am still involved in the crisis that occur	Apr 16, 2011 7:37 AM
34	My son's co-workers at his job at Walgreens provide natural supports so my son does not need a job coach.	Apr 16, 2011 9:07 AM
35	Babysitters can handle her physically after surgery like now. Most of the time, grandparents can help but not during times when she is more physically dependent.	Apr 16, 2011 11:02 AM
36	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
37	personal support worker thru HBW	Apr 16, 2011 6:45 PM
38	synagogue	Apr 17, 2011 5:20 AM

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

39	We were able to hire our son's aide from school to help on occassion. 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
40	I receive a limited amount of help from church, neighbors, and friends - my closest friends are also caregivers of children with disabilities, which greatly limits the amount of support they can provide.	Apr 17, 2011 12:10 PM
41	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
42	College volunteers from a religious club	Apr 17, 2011 8:29 PM
43	I'm in a circle group	Apr 17, 2011 10:50 PM
44	I have friends, but most have their own kids with disabilities and it would be wrong to impose on them.	Apr 17, 2011 11:19 PM
45	1 grandmother 2x a year.	Apr 18, 2011 7:21 AM
46	Our Daughter	Apr 18, 2011 8:21 AM
47	I only have one daughter in town who can help me in an accute emergency, but I cannot rely on her for much support due to her own schedule (student).	Apr 18, 2011 9:24 AM
48	I have one person I can call only if it's an extreme emergency; I have one neighbor that will get him off the bus if she is home, until the Direct support worker can get there if she's tied up and is a few minutes late for the bus. My husband and I are only other supports for our son.	Apr 18, 2011 10:45 AM
49	Son's dad who is a co-guardian	Apr 18, 2011 10:45 AM
50	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
51	we have family and friends supports but cannot rely on them "regularly", only occasionally.	Apr 18, 2011 12:57 PM
52	I have some (little) natural supports that I don't have to pay out of pocket for. Most supports from friends who assist with babysitting/respice I have to compensate them.	Apr 18, 2011 1:17 PM
53	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 daugther's problems do not lend themself to natural support help. My daughter's father lives 5 miles away and works.	Apr 18, 2011 1:30 PM
54	school	Apr 18, 2011 1:31 PM
55	People will help occasionally, but not regularly.	Apr 18, 2011 2:07 PM
56	A few now and then but not regularly available to fill in when his occassional staff is not available.	Apr 18, 2011 2:18 PM

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

57	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
58	Once in a while my other daughter can watch my two children with special needs.	Apr 18, 2011 2:47 PM
59	Parent to Parent families	Apr 18, 2011 3:33 PM
60	for socializing but not for caregiving	Apr 18, 2011 4:58 PM
61	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
62	coworkers	Apr 19, 2011 6:32 AM
63	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
64	I have 2 people who will help, not regularly, and they are in their seventies.	Apr 19, 2011 9:02 AM
65	Only have siblings as both parents are deceased and all siblings care for youngest who is disabled	Apr 19, 2011 1:14 PM
66	school	Apr 19, 2011 4:11 PM
67	DSACO, autism group	Apr 19, 2011 5:01 PM
68	Supported Living funded thur the Regional Center in California	Apr 19, 2011 5:44 PM
69	support groups	Apr 19, 2011 6:11 PM
70	school	Apr 19, 2011 6:24 PM
71	spouse	Apr 19, 2011 8:19 PM
72	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
73	Other parent of child with disability Occ with school employees	Apr 19, 2011 11:24 PM
74	Direct Support Worker	Apr 20, 2011 8:43 AM
75	my mom but she works and has been sick	Apr 20, 2011 9:14 AM
76	NAMI	Apr 20, 2011 9:44 AM
77	Family will help on occassion or if Emergency	Apr 20, 2011 9:56 AM
78	Relative	Apr 20, 2011 7:36 PM

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

79	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
80	very limited. other people help but don't understand all the time needed	Apr 21, 2011 12:45 PM
81	We have a few people that we pay once in a while out of pocket	Apr 21, 2011 12:53 PM
82	only receive sporadic support, not regularly dependable or desirable.	Apr 21, 2011 2:01 PM
83	Paid sitters	Apr 21, 2011 6:32 PM
84	ACAP-adult community autism program, I get no support from any other of the above	Apr 21, 2011 7:36 PM
85	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
86	disability community	Apr 23, 2011 12:30 PM
87	We have Mobile therapist, waiver support, and church people that are helpful with our son.	Apr 24, 2011 6:48 AM

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

1	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	They don't exist	Apr 13, 2011 8:25 PM
4	We are the natural supports and the necessity is lifelong. There are more and more needs with 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
5	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
6	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
7	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
8	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

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

9	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
10	The school system should be a natural support since my child spends 8 hours a day there, 5 days a week. "In loco parentis" doesn't seem to apply to many school officials.	Apr 13, 2011 9:51 PM
11	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
12	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
13	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
14	When it comes to people who have very complex disabling conditions where "progress" is minimal or absent, "natural supports" burn out. When your family, friends, co-workers... tire of hearing about what is needed, it is very hard.	Apr 13, 2011 10:51 PM
15	In my case people are too afraid to watch my daughter as they cannot take care of her 24/7 needs and are just afraid of being responsible for her, and it's not as simple as watching a cute child who can take a nap and eat whatever she wants and you can do whatever you need to with your day. She doesn't walk well, doesn't talk, her blood sugars have to be monitored, her free water intake has to be monitored every bowel movement/urine output must be monitored, amounts of food and eye ointments, and therapies (3x a week.) And it takes a lot of understanding medication and what to look for and how to deal with it. She is non-verbal, diabetic. The only person willing to help me was my mother in law. And even she cannot watch my daughter over night or past 8 pm as there are medications that have to be given and she draws the line at being responsible for this set of medications. I am military and sometimes am required to work shift work with little notice. And it becomes a challenge if my mother in law cannot watch my daughter. I have no one else. It's not that they don't want to help. They just don't feel capable enough to help. It's medication, food types, sign language, responses, schedules, logs. And they just can't keep up with it. I am very blessed to have someone who is willing to try to learn even if they get it wrong, they bounce back instead of giving up. But I know many many people have to quit work to care for their children because no one can take on the full time responsibility. If I didn't need the income to afford for my other children, I would have to stay at home with her. Even though she is self moving and able to feed herself. The amount of 'other care' that is needed goes beyond what a daycare would be able to handle but doesn't qualify for in home nursing care programs. And I can't afford a medically trained Nanny.	Apr 13, 2011 10:56 PM



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

16	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
17	We get sympathy but no really help from family, friends etc. They think the gov't takes care of it all and have no clue.	Apr 14, 2011 6:37 AM
18	I had this in new york	Apr 14, 2011 6:43 AM
19	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
20	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
21	while family and neighbors and friends have provided support in many ways it never involves directly caring for my son. My sister used to but ever since he pulled her hair she ha stopped and makes me feel guilty for asking	Apr 14, 2011 7:46 AM
22	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
23	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
24	Natural supports are great when available. They must be nurtured, and as the sole caregiver I do not have time to nurture these relationships. My teen-age son has outgrown the cute stage. We live in a small mountain community. People in the community will rally with support in times of great need (like if I had to go to the hospital), but on a day to day basis I am on my own. For example, I can hardly even get outside for exercise because I am afraid to leave my son alone in the house. There have been times when I have gone outside to fill the birdfeeders, which are right noxt to the house, and walked back inside to a 'disaster.' Now that he is eligible for adult services he is on a waiting list for agency supports that are only provided in a community 45 minutes away. Yikes. The church has been of no support, the child's mom left because she was bored with his disability, my parents are aged and have their own needs for support. I am tired, but still here.	Apr 14, 2011 8:26 AM

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

25	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
26	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
27	sucks when you are seeking services from an agency and they tell you to use your family.	Apr 14, 2011 8:44 AM
28	My nearest immediate extended family is one hour away, which makes it only useful for occasional help, but certainly not helpful for daily care issues. And not at all reliable when the weather and roads are bad! It's hard to find friends who are willing or able to help take care of my daughter with their busy lives.	Apr 14, 2011 8:55 AM
29	It's a nice concept, but not everyone has families who can or want to assist.	Apr 14, 2011 9:00 AM
30	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
31	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

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32	<p>My son has severe Autism with severe behavior issues. He also takes a lot of medications. He is non verbal and very aggressive. When he was only 6 years old, I asked my neighbor to watch him for a short while. My sister, who also has no one else, had fallen and needed to go to the hospital emergency room. When I returned home after about 3 hours, my neighbor was fine but said that she was in awe of my strength and courage and how hard it was to take care of my child. She said she wasn't comfortable and she was sorry, but she couldn't watch him again, ever. Another time, before I started working at Bright Horizon, the Broward Center School for children with disabilities, were I now hire my respite workers because I am on CDC+, I had been given an agency that would give me a few hours a week, The girl they sent had not been trained at all, and it was her first job. Realizing this I was uncomfortable leaving my son with her, but I really need to go up to the grocery store, I was gone no more than 45 minutes. When I got home the girl was on my front porch with her car keys in her hand, and ran to her car the moment I pulled up. I went inside to find my son in a soaked diaper with a 2liter bottle of Coke. Later when I called the girl, she said that my son tried to hit her in the head when she went near his diaper, and he took the soda from the refrigerator so she let him. She also said she wasn't coming back, like a would ever ask her again. Another bad experience with another agency was when another new worker called the police because my son bite her while she was trying to get him on the bus. My son, due to his disability, doesn't understand social interaction, he is tall and heavy, much larger than me, and he has no understanding of his strength or hurting someone. I can not ask anyone to watch him, he is 16 1/2 year old, wears diapers, has trouble with bowl movements, so they usually are soft and go up his back requiring a shower, he can get aggressive, even if someone has good intentions the can not handle my child, again , due to his type of disability.</p>	Apr 14, 2011 10:26 AM
33	<p>Family members are non-supportive. I tried the church and recvd the "just pray" support which didn't help my child or myself. Friends have their own lives and are not available to assist.</p>	Apr 14, 2011 11:06 AM
34	<p>Would have loved natural or unnatural support. I had no respite care, no competent after school care.</p>	Apr 14, 2011 11:13 AM
35	<p>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.</p>	Apr 14, 2011 11:15 AM
36	<p>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.</p>	Apr 14, 2011 11:20 AM
37	<p>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.</p>	Apr 14, 2011 11:28 AM
38	<p>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'.</p>	Apr 14, 2011 11:30 AM

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39	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
40	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
41	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
42	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
43	Family have proven unwilling and unable to assist competently with any level of care. Neighbors and others who are not professional caregivers are not consistently available in our situation despite our participation in a close knit community that creates a lot of natural supports for non-disabled children and community members.	Apr 14, 2011 12:20 PM
44	My mother and father help me and my husband with out 4 year old autistic son. However, that help is just respite care, not actual therapeutic help which he so needs but is unable to get because insurance companies have found lots of ways of not paying for it.	Apr 14, 2011 12:29 PM
45	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
46	We live in a different state than other family members so they are not able to help out on a daily or as needed basis. We do have friends in the area but they are busy with their own lives and it is difficult to depend on them for help except in short-term emergency circumstances.	Apr 14, 2011 1:05 PM
47	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
48	It would be nice if my daughter had friends and not just family	Apr 14, 2011 1:44 PM
49	I do not have anyone who is a 'natural support' for the kind of home health specific support needed. That is primarily paid support. But do use natural supports for social and work experiences	Apr 14, 2011 2:08 PM
50	It takes a lot of work to use "natural supports" ie friends, family to provide care to our son. They are willing but it takes a lot of planning and our son is not always comfortable with the care they provide. He is safe with them but they don't do things the way he is used to them being done, thus creating him to worry more.	Apr 14, 2011 3:37 PM

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51	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
52	Natural supports is a great idea - except either there is no family available, neighbors don't want to take on that responsibility, all responsible adults work, siblings are not old enough to take on the responsibility, etc, etc, etc. I'm it!! And I'm only it because of the state payments I receive to maintain the home the person with disabilities lives in and has lived in for 10 years.	Apr 14, 2011 4:41 PM
53	I have over 30 disabilities, and I'm only 18. So having natural supports helps me a lot. If it wasn't for my natural supports, I would have not graduated high school, & find and keep a full time job. The people who don't have disabilities need to know that natural supports & federal programs make us disabled people ABLE to function with little to no support.	Apr 14, 2011 4:55 PM
54	When you have a child with an ongoing chronic disability it seems to much for others to handle and they bail. I would LOVE to have natural supports but my energies are taken up taking care of myself and my children. It is very hard to forge friendships when they KNOW you are going to need their help. This is a real friendship killer. In the past, the "natural supports" I had seemed to think they KNEW how to make myself or my children better or gave words of advice where they were ignorant of the actual issues surrounding our disabilities. I have yet to find a someone who is in it for the long haul and can support me without tearing me down.	Apr 14, 2011 5:09 PM
55	very hard to find people willing to help with little pay	Apr 14, 2011 6:17 PM
56	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
57	I feel isolated and ostracized a great deal of the time. I have a very small group of ppl whom I would consider "natural supports." There is a larger group who say they would like to support my family and I but are reluctant to step up. When asked to assist/support most often have a myriad of reasons why they can't. This happens often enough so I have, pretty much, stopped asking at all. If I can't buy the support, I don't have the support. Continuous and constant rejection are no longer my cuppa tea.	Apr 14, 2011 8:03 PM
58	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
59	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

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60	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
61	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
62	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
63	Everyone is too busy with work and maintaining their own health and families to offer us anything more than moral support! I have TWO DD young adults living at home. No family or friends EVER offer to provide respite!	Apr 15, 2011 7:29 AM
64	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
65	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
66	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
67	What does natural supports even mean? We have no disposable income. We do pay for health insurance and we take advantage of it all the time, but it does not provide for therapeutic benefits like PT, OT, and speech therapy.	Apr 15, 2011 8:46 AM
68	People are willing to help on occasion, but on occasion help is not properly trained and cannot remember specifics between time to time. Most people are already VERY busy with their own lives, in school, working extra hours to pay for increasing prices lately of gas etc and can't afford to give regular time and help.	Apr 15, 2011 8:54 AM

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69	We are extremely fortunate to have family close. If we ever move that support would dry up overnight.	Apr 15, 2011 10:05 AM
70	people in the community	Apr 15, 2011 11:58 AM
71	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
72	When kids are little, natural supports seem easier. When they enter middle school and beyond, it seems harder to find an KEEP them. Now as I look ahead to post high school support, I am fearful that all these supports I have in place will go away. in Reality, grandparents age and get sick or die, siblings go off to college and their own lives, as do age cohorts and friends...I wish I had known 5 years ago what kinds of employment development supports I would need for my child NOW. I would have done some things differently in the transition part of my child's HS career.	Apr 15, 2011 2:01 PM
73	I have been blessed to live in an area that allows me (a parent) to be a paid caregiver. This has allowed my son, who has severe disabilities, with reliable, consistant, quality care! Of course, we have to stay on top of what's happening with legislation to be sure we don't lose this.	Apr 15, 2011 2:53 PM
74	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
75	it would have been nicer to be able to choose from multiple ages since i have more than one with a disability. if the gov't wants to push people to use natural supports which i believe means family and friends (if you're lucky to have them) instead of agencies, you might as well provide more mental health benefits because a lot of people are going to go crazy and depressed etc.	Apr 15, 2011 3:14 PM
76	As a military family, we are far from extended family who would otherwise be "natural supports" and I have only asked friends to care for my child during moves.	Apr 15, 2011 3:52 PM
77	We used to live in Idaho, with family more than a day's drive away. We moved across country, closer to family, and yet grandparents are still one hour away. They help as they have time; still working. Other grandparents live 3 hours away, retired, and have no idea the work we go through for our son. Friends do not fully understand... Caring for our son with autism is a strain on our family, and on our marriage -- but, we would have it no other way. My husband and I often "tag-team" with our son, so time together to keep our marriage going is a commodity. Babysitters are not an option. Thankfully, we do have Personal Care Attendant hours, which help is giving me (Mom) a break. Still, PCA is not meant for babysitting, so does nothing for our marriage or family (we have 2 other children).	Apr 15, 2011 3:56 PM
78	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

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79	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
80	If perhaps I could get some support i wouldn't feel so burnt out!	Apr 15, 2011 5:48 PM
81	It was easier when he was a little guy. Then it was just "babysitting" even though he was 10 or 12 at the time. Once the puberty happened and he was trapped in the world of no age ( still likes things that 8-10 year olds like but is 22) there are no natural supports unless there is money or some reward provided. No one knows how to deal with him. People at church love him at church but there is no activities outside that venue. The people he works with love him but don't socialize with him outside of work. He still has some friends from school that will come to visit him if we have a party at our house or some venue in Denver, but no socializing or anything from them spontaneously or no inclusion in activities they are doing anyway. So tell me what are his natural supports and how do we access them??? I think money is the only language that is spoken in "natural support land"	Apr 15, 2011 8:52 PM
82	For me, a lot of it comes down to my daughter's willingness to let me and her dad out of the picture and to willingly receive assistance from others we may recruit when we're tied up otherwise.	Apr 15, 2011 9:24 PM
83	Very important for social relations and going out. At home it's always more easy !!	Apr 16, 2011 12:49 AM
84	My husband and I live about 40 miles from family. Of the family, only my adult nephews are physically able to care for my son. He is a runner and needs assistance to toilet, feed himself, etc. When he lived with us (until 6 months ago) and we had an event where they live, we have taken my son to them for a 2-4 hour visit. Other than that it was easiest to hire capable, willing people to spend time with him near home. Our son always does best with routine and familiar surroundings--I think it makes him feel safe, he knows what to expect. He doesn't crave variety.	Apr 16, 2011 5:52 AM
85	Persons close to my family are loving and caring towards my son, but do not know how to help him socially or therapeutically.	Apr 16, 2011 6:05 AM
86	Our son has a very rare chromosome disorder with a lot of mental health issues. Physically he looks normal. It is very difficult to get immediate family, friends, or anyone who is not around him everyday to understand the full scope and complexity of his disability. The people who do fully understand are very hesitant to help because of the difficulty and stress, and others view him as a normal child who has issues due to poor parenting.	Apr 16, 2011 6:13 AM
87	The support is recent, and follows years of terrible disappointment from hoping to get natural supports from family.	Apr 16, 2011 6:20 AM



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- |    |   |                      |
|----|---|----------------------|
| 88 | <p>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.</p> | Apr 16, 2011 6:58 AM |
| 89 | <p>While my daughter was developing language, there was no one that we could leave her with for time out as a couple or time with our other children. Now that she is a better advocate for herself as a young teenager, (and we can leave her alone with technology as a support) this isn't such a big issue, but like parents of any child with special needs, she doesn't have as much access to what's going on in life without us present. Eventually we found other parents of kids who are deaf/hard of hearing, who were a huge support to us, and now we offer that support to other families with younger kids. We did not find support at church (some amazingly ignorant responses from people there) or among our co-workers, and while both sets of extended family love her (and us) they live too far away to be a real support and have never learned how to communicate with her on a deeper level. I know this is minor compared to parents whose adult children require 24-7 supervision and assistance but wanted to add to the survey. Thanks for asking!</p>  | Apr 16, 2011 7:07 AM |
| 90 | <p>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.</p>  | Apr 16, 2011 7:15 AM |
| 91 | <p>Nobody wants to help because the amount of work involved with my child.</p>  | Apr 16, 2011 8:20 AM |
| 92 | <p>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.</p>   | Apr 16, 2011 8:25 AM |
| 93 | <p>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.</p>  | Apr 16, 2011 8:39 AM |

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

94	We have no extended family where we live. I have been informed as to where to find Personal Service Workers, but have not followed through at this time. I rely on my sons' older sister as a natural support. It would be a big step for me to reach out to other people as would be required to form a Microboard or on a smaller scale to find personal service workers.	Apr 16, 2011 9:07 AM
95	Natural supports will not work for my relative due to the level of severity and her living situation.	Apr 16, 2011 9:58 AM
96	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
97	more avenues to obtain support is desperately needed!!!! I NEED HELP!!!!	Apr 16, 2011 12:37 PM
98	We have family and friends in the area and we belong to a church group. So we have many people who could qualify as "natural supports." But the reality is that family does not feel comfortable with our kids, church people do not know our kids well enough to be comfortable with them, and friends would help but have other responsibilities of their own.	Apr 16, 2011 12:49 PM
99	In our case the "natural" supports we receive are household chores help, 1-2 hr line of sight watching of our special needs child, and taking siblings of our special needs child to and from activities so I am free to care for my special needs child. It is a support, but it is not direct care of our special needs child for the most part. My parents, who are our "natural" supports are in their mid-seventies, so soon their own physical limitations will not allow them to even help us in the ways they do now.	Apr 16, 2011 1:39 PM
100	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

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

101	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
102	I have natural supports that can be counted on for short periods of time in case of an emergency. None of my natural supports could be counted on to provide regular, ongoing, volunteer support. My son's needs are too extensive to ask someone not related to him to undertake.	Apr 16, 2011 3:12 PM
103	I developed natural supports on my own instead of a training	Apr 16, 2011 4:35 PM
104	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
105	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
106	We don't receive any paid supports so we've been forced to get creative. Our 8 year old daughter is non-verbal and medically complicated with multiple disabilities. Her friends have become great natural supports both at school and here at home. They play together at our home which frees me up to do chores, and they go on errands and trips with us. I really hope we can keep this going over time.	Apr 16, 2011 6:37 PM
107	Care providers are threatened by these supports.	Apr 16, 2011 8:15 PM
108	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
109	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
110	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

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

111	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
112	Natural supports are only really available on a once in a while need, but noone in our 'natural support' system would be willing to take on full time care.	Apr 17, 2011 8:02 AM
113	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
114	I am a single parent-there is not enough time in the day or lifetime to do it all. I guess I don't have as many friends or neighbors as those who promote/prag about the natural supports they have established for their child - my friends and neighbors also have a lot on their plates... A typical parents fear would be that they survive their child - as terrible as it sounds I am afraid that my child will survive me - my nightmare is the image of my woman child (unmedicated) living on the streets, pushing a grocery cart loaded with her most precious toys. Having said this, I am incredibly fortunate to have a nephew with a gentle heart, who has clearly asserted that my daughter will not live with strangers rather she will live with him, his wife and child(ren) - therefore I have named him as the beneficiary for my retirement monies once I am dead (50% for his lifetime) and he will also inherit my house to live in or sale - in the end it is a "crap shoot" - however, I believe that I trust his intentions over the intentions of any agency or beurocracy.	Apr 17, 2011 8:32 AM
115	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
116	I, myself, am a mother with significant CP, and I have two children. No family in CO. As my daughter's seizures and other delays progress, my friends become less willing to assist. I use attendants to meet my own needs, but I find it increasingly difficult to even shower, because there is no one to supervise my daughter. Medical Needy kids and "natural supports" is often not practical.	Apr 17, 2011 10:58 AM
117	I like the concept of natural supports, but it's much more difficult for some to develop than others. My adult daughter has very limited communication, several personal care/health needs, and unusual behaviors (very stressed by new situations/changes in routine; when really upset, may hurt herself or others) and we've moved a number of times due to job changes/layoffs. Her only sibling is in the military (out of state and soon to be deployed overseas); our nearest relatives are 10 hours away. Most of our friends are other families with children with disabilities, so their help is limited. It was much easier to find supports for her when she was a cute/quirky 3-year-old (her disorder has been regressive; she has many more needs now); a few people have offered help but I am not sure they could safely manage my daughter.	Apr 17, 2011 12:10 PM
118	It is easier for us to use family members as supports since they live locally and have expressed their willingness to help out. I know many families for whom this is not the case. We don't have much extra money, so if a family member can't help us to watch kids, then we are rarely able to pay for babysitters and so don't go out in those cases.	Apr 17, 2011 2:57 PM

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

119	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
120	I agree with the theory of natural supports, but it doesn't pan out in reality.	Apr 17, 2011 4:33 PM
121	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
122	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
123	As my son has gotten a bit older and has become more manageable, I am better able to rely on family and even occasionally ask something of friends and neighbors. When my son was hospitalized the first time, neighbors told me that their church group prayed for him and this continued for years as he never recovered. Friends cooked us meals but this dropped off as it became less of a crisis and more of a sad but everyday reality. From a research prospective I feel that this survey has an inherent bias and anger towards "the system" for trying to substitute free natural supports for state provided services. With that, even if your survey supports your premise that natural supports are lacking and insufficient to substitute, I don't think anyone from "the system" would find your survey methods credible or valid, just by the way your questions are phrased and leading. Though I appreciate your efforts!	Apr 17, 2011 8:29 PM
124	Should be an early childhood term only. The older a child gets the more natural supports disappear. Not there especially for individuals with behavioral or medical needs.	Apr 17, 2011 9:36 PM
125	i'm interested in doing public speaking	Apr 17, 2011 10:50 PM
126	I only answered number 6 with "never" because I refuse to let anyone make me feel guilty about my family situation. Reality is, though, I will not be able to keep up this level of care forever. It is exhausting, both mentally and physically. Unfortunately, I have no doubt that my son will receive very few services because he IS cute and chatty with other adults. He is only difficult if you ask him to do anything. Of course, life requires us to do things. The basics, like eating, staying dry at night, understanding money, laundry, transportation, and cooking are a constant difficulty. Even if my family lived close, they couldn't handle his anxiety and frustrations, plus his constant needs would overwhelm him. As for church, they don't get it. They think if they don't kick him out of the youth group they are helping. They don't realize that he won't stay if he is not included with respect because it won't be fun. It becomes just another place that he feels unwanted. Plus, they always want me to volunteer because they don't know how to handle him. I never get a break away from him. So much for natural supports.	Apr 17, 2011 11:19 PM

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127	Natural supports would be wonderful if everyone did not have their own life with no time to help .	Apr 18, 2011 6:26 AM
128	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
129	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
130	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
131	Natural Support. That is a joke, right? What support?	Apr 18, 2011 6:41 AM
132	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
133	I think we all want the best for our kids. I just wish they didn't make it so hard not to feel quilty and so expensive to get the help we need.	Apr 18, 2011 6:49 AM
134	Most of those that would be considered "natural supports" are not willing to care for my son because of his complex medical needs.	Apr 18, 2011 6:52 AM
135	no comments now.	Apr 18, 2011 6:57 AM
136	I haven't sought training on "natural supports". My family just isn't an option. Paternal grandparents are dead, even the child's father isn't the most helpful. For some families, there is just no such thing as having natural supports.	Apr 18, 2011 7:10 AM
137	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
138	We as parents should have special training classes for our natural supports so that they could have a better impact.	Apr 18, 2011 7:16 AM
139	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

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140	with out my church I would have none..not sure where to look for them	Apr 18, 2011 7:26 AM
141	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 aer trying to explain to them, so usually I stuggle with it myself.	Apr 18, 2011 7:35 AM
142	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
143	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
144	Just because someone has family members that they spend time with doesn't mean they will help. I know people who have family members that are not willing to help and some their family members are older and the are not able to help. And as I said some just won't help, they don't want to help or be bothered by what it takes to take care of someone with a disability. Just because they are your natural family doesn't mean they are compasionate, caring or giving. It may seem odd to those that have a wonderful natural support system but in some family's their own family is just as prejudice and uncaring as the rest of the world who really don't care about people with disabilitys or who are embarrassed by them.	Apr 18, 2011 7:55 AM
145	Afraid to use natural supports from Churches. All my older kids were sexually abused in a Church on a systematic level without my knowledge at the time.	Apr 18, 2011 8:01 AM
146	It is hard for natural supports to know how to handle our child at times.	Apr 18, 2011 8:08 AM
147	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
148	My husband & I are the natural supports. I would love to have qualified peoplr 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
149	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

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150	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
151	I believe that it should begin at the developmental disability start of pre-k and evolve with the individual child. This would allow the parents to grow with the system and instruct them on using these supports.	Apr 18, 2011 8:44 AM
152	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
153	Three of my son's grandparents are deceased - and obviously not a support. The remaining Grandmother is 85 and unable to care for a person with a profound physical disability. My son's brother and sister are away at college and cannot help. His Aunts and Uncles all work full time and have families of their own to care for. Most importantly, my son with a disability has profound quadriplegia and our family and friends are "afraid" to take care of him for fear that they will "hurt themselves. I am not being pessimistic when I say - we have no "natural supports" Quadriplegia is not "natural"!	Apr 18, 2011 8:50 AM
154	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
155	I utilize my adult daughter as my natural support but this takes a toll on her as well. We have other children but very seldom are we able to "go out" for a "family" function. Our daughter is medically fragile and thus cannot travel very well. My adult daughter also helps me care for my younger disabled daughter with things such as bath time. I cannot lift my 80 pound child by myself. Sometimes I worry about the load that I have placed on her but I do not know what else to do or who else would help.	Apr 18, 2011 8:58 AM
156	Only "natural" supports in case of an extreme emergency. Day-to-day "natural" supports are not available.	Apr 18, 2011 9:09 AM
157	Natural means unforced supports. It seems as though the state wants to force families to take care of a brother or relative whether they can or not.	Apr 18, 2011 9:20 AM
158	Think school system may have a tendency to over-rely on natural supports in lieu of providing appropriate services, referrals, accommodations, and modifications. Also, People with Disabilities (and Parents/Caregivers) should receive more info. training about natural supports (training/gaining), as well as, terms that imply/refer to these concepts. Thanks to Carol Calix of Families Helping Families (NOLA) for sharing this Denver Fox, EdD. insightful natural supports survey.	Apr 18, 2011 9:22 AM



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159	I have almost no family in the area and of those that are here, only two could help IF there was an acute emergency. They are either working full time or are students. It's very frightening to know how little I have in natural supports in case of an emergency where I couldn't care for my daughter with special needs.	Apr 18, 2011 9:24 AM
160	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
161	I have reached out and found these supports. They do not spring up automatically. They take work to cultivate and nurture. It cannot be assumed that everyone has these, or is capable for forming these.	Apr 18, 2011 9:44 AM
162	Food allergies are still not very well known and people don't understand their severity and that they are a disability, even to those closest to you, your "natural supports." It is hard to trust other people, even those closest, to really understand how to keep your child safe. It means that my husband and I rarely get to do things outside of our home and taking care of our child. There are very few support groups for food allergies and little to no "training." What you learn you have to seek out yourself.	Apr 18, 2011 10:02 AM
163	While my mother was alive (she died 5 years ago) we had a WONDERFUL natural support in her. She had a close and loving relationship with our daughter, now 22, who has severe autism, and spent time with her minimum twice a week, doing favored activities that both enjoyed. She was a huge help to our family. Her death was a huge loss for many reasons, and we miss her dearly.	Apr 18, 2011 10:23 AM
164	I have family but I feel they are not capable of caring for my little girl. It is very hard to navigate the world of caregivers to find someone appropriate to help with her when we need it.	Apr 18, 2011 10:40 AM
165	You spend so much time dealing with schools, doctors, therapists, and on and on, there's not much time for your socialization so how do you build relationships that lead to natural supports?! The relationships I've formed are with others in my same boat because we cross all the same paths. My friends all have at least one child with a severe disability and three friends have 2 children with severe disabilities. They are looking for support themselves. My sister lives too far; my parents are too elderly. Relying on natural supports is fine if you have them. But if you don't, there has to be help. It's too overwhelming.	Apr 18, 2011 10:45 AM
166	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
167	Natural supports don't do any good if they are a thousand miles away! All of our family lives out of state, therefore, there is actually no natural support to help us! Besides, is it not the school system's responsibility to help us educate our son?	Apr 18, 2011 11:07 AM
168	I feel like I can rely on support from friends for simple tasks, but not for anything major.	Apr 18, 2011 11:08 AM

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169	I think the other question is to define natural supports... parent support, respite care, understanding, help with other children, financial help... there are so many things families with special needs kids may need help with! While natural supports are sometimes available for me... I have had offers to have ladies from church come in and help with my son... My concern about using more of the natural supports I could use, is the negative impact it could have on my son and then in turn our family life. At this time and with his issues having multiple people helping care for him would not be helpful! It would require lots of time on my part to train caregivers for just a short time of help... Supports i do use are my parents, they will help with my other son; if they are not working! My church helps provide food for my family...	Apr 18, 2011 11:41 AM
170	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
171	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
172	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
173	I have nothing constructive to say. My mother taught me that if I have nothing good to say,I shouldn't say anything.	Apr 18, 2011 12:59 PM
174	I've never had anyone ask or suggest natural supports.	Apr 18, 2011 12:59 PM
175	I don't think natural supports should replace in-home community based services. Thank god our relatives will provide some supports but if we went back to that well continuously or without compensation it would dry up fast. We still need community based services (fee based) to supplement natural supports. Remember it takes a village to raise a child with special needs.	Apr 18, 2011 1:17 PM
176	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
177	Never heard of Natural Supports ? I have two kids on a IEP at school both have anxiety, depression, A.D.D. and they have to read out loud to learn and school teaching methods are not working so they read at 3rd level in the 7th and 10th grade	Apr 18, 2011 1:43 PM

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178	Most natural supports run like hell when they see you coming, avoid the phone when your on the other end, or pretend not to hear the door when you knock. Our child is a handful to say the least, they wear us out in no time at all and we are supose to be 'used' to it. What do you think the parent who is not acustomed to it feels like? In thirty minutes they are watching the clock tick by and biting what is left of their nails off, waiting for you to get back. Paid respite is hard to find, free respite is almost unheard of. It takes a very special family member, or other 'natural support' to be there and be there often. It's a hard job, we try not to complain often, but when you cut an already short budget it makes one angry!	Apr 18, 2011 1:46 PM
179	Natural supports come in a variety of ways. Your survey needs more open ended questions. Sometimes people try to be helpful and end up only adding stress to a situation. Others that totally understand, can be supportive just by not judging.	Apr 18, 2011 1:59 PM
180	Most of the support that my daughter has is my support. The other support systems available all cost extra money which I generally provide.	Apr 18, 2011 2:07 PM
181	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
182	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
183	I have been a parent of children with special needs for over 23 years, and I am a professional in the disability field, and I still do not understand what the term "natural supports" means exactly. I do not have extended family members to support me, and I do not have the funds to hire a live-in nanny, if that's what "natural supports" means. Therefore, I have very little support unless my college age daughter can watch the kids so I can get a short break.	Apr 18, 2011 2:47 PM
184	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
185	Family too busy	Apr 18, 2011 3:02 PM
186	up until our school got into trouble we didnt even seperate the high school retards as they were called from the little ones.	Apr 18, 2011 3:21 PM
187	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
188	My parents are older and won't we able to help much longer. Then we will have no one. We are on AR waitlist.	Apr 18, 2011 3:42 PM
189	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

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

190	we only have one ( his sister- 18yr old) who is able to provide the"natural supoport",but to her decline in her health, that will stop in time. When the support is completely gone- I the Mom will be the one to support. Luckily, he is able to stay home for short period of tme along. This gives his dad to make it in when necessary.	Apr 18, 2011 3:56 PM
191	Full time grad student and never heard "natural support", very poor support group for diwn syndrome in Shreveport	Apr 18, 2011 4:07 PM
192	Our family is very small and lives all over the US so there is no "natural support" from that. Our church loves us but no one there has the training to deal with our son and his disabilities. Natural supports is a ridiculous term that people in the system have created to try to blame parents and families.	Apr 18, 2011 4:58 PM
193	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
194	What I have learned is from other parents of children with disabilities.	Apr 18, 2011 6:44 PM
195	So called "natural supports" are fine as a back-up, but as individuals with disabilities age, that support disappears. As parents/caregivers age, they have less and less access to true support for an adult child with significant challenges. This is NOT a solution, or a replacement, for paid community support from caregivers who are trained and understand the expectations of individuals with disabilities and their families who have a right to an independant life.	Apr 18, 2011 7:35 PM
196	Though my child has several disabilities, the effects on her are at this time still mild compared to many others. Even so, we struggle to find her the help she needs. Our best support is one neighbor couple. Apart from them, we have few others to call for support.	Apr 18, 2011 8:20 PM
197	We've settled in Colorado many states away from extended family, but even if we lived near, they would not be able to help in a significant way. "Natural supports" sounds very scary to me. My kiddo currently has OT, PT, speech, and a g-tube, no one in our lives is currently able to do this in any form "naturally." If we all had these "natural supports" would there be any need to train paid professionals? And I also think about when my daughter gets older and much less cute, who's going to help out then? When I can't carry her anymore.	Apr 18, 2011 11:03 PM
198	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

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

199	I think it is asinine to think that the disability services system which has never been fully funded will be there to fund every one of us. I think it is our parent duty to support our children, but that doesn't mean that there shouldn't be some support from the system as well. We all need a healthy balance in our lives of paid and unpaid supports. This shouldn't be any different for my daughter who has significant support needs. In our state, there is no equity - she gets no services, beyond special education, that support her or our family the other 158 hours of the week while lots of families get an overabundance of funding and services. We "make too much" to qualify for SSI. She can "sit on a waiting list" for decades for Medicaid Waivers, but why bother when the services are pre-defined and not what she might need. Why this reliance by everyone on Medicaid?!	Apr 19, 2011 4:08 AM
200	Nonverbal, behavior issues, make it very difficult to find willing unpaid supports.	Apr 19, 2011 4:51 AM
201	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
202	"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
203	"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
204	"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
205	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
206	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 goverment 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

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

207	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
208	They would be great if they were there. Sometimes, it just isn't possible because there are no natural supports.	Apr 19, 2011 7:00 AM
209	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
210	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
211	Having natural supports that truly want to be involved in the care of your loved one is a rarity.	Apr 19, 2011 7:20 AM
212	I think most people think it is as easy as 1-2-3...just going out, meeting people, & BAM! There is your social network. If you are not in the life of raising a child w/ a disability, then one will never know how utterly difficult it can be to connect with others. The truth is that some people, yes, even family, do not want anything to do with you, or it might not be healthy to be around their negativity. Any way you look at it, "natural supports" is not the answer, nor will it ever be.	Apr 19, 2011 7:41 AM
213	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

**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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| 214 | <p>Last year we changed churches because there was little support where we were. As our daughter entered the church youth group the leaders were not willing to provide the supports she had received as a child in the children's program of the church. The church we sought and found has wonderful supports. She participates in the weekly youth group meetings and will go to summer camp with the group. A specific individual who is a behavioral assistant will be accompanying the group as a counselor, I didn't even have to request such support! I think supports can be found, however they are inconsistent and sometimes require major upheaval to the family. We are older parents with other grown children so they are also a support rather than a hindrance to seeking supports. They do have their own families, though, so we don't like to impose on them too much. Our daughter's girl scout troop has also been a good support. We used to pay someone to accompany the troop camping, but she has now camped twice with just the troop and leaders.</p>  | Apr 19, 2011 8:20 AM  |
| 215 | <p>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.</p>  | Apr 19, 2011 8:27 AM  |
| 216 | <p>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.</p>   | Apr 19, 2011 9:02 AM  |
| 217 | <p>I don't have many natural supports for my son. This idea is ridiculous.</p>   | Apr 19, 2011 9:02 AM  |
| 218 | <p>My son is too severe for someone to want to care for. If there is an absolute emergency, I might be able to get someone to watch him for an hour. No one wants to get beat up or chase a child down the road for even what respite workers and behavioral assistants are paid. I have offered to pay friends and they still say no way</p>  | Apr 19, 2011 9:37 AM  |
| 219 | <p>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.</p> | Apr 19, 2011 10:06 AM |

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

220	We are living in rough economic times. Outside of my immediate family, which includes 2 disabled adults, and 3 special needs children, I have one friend (who has one special needs child), who can occasionally offer a helping hand. I spend the majority of my day advocating for a free appropriate public education for my 3 school aged children. I try to spread out my time to be available for each child. I do find many teachable moments. I get very little sleep at night due to the latter. I have a college degree. Natural supports, for most families, is negligible.	Apr 19, 2011 10:28 AM
221	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
222	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
223	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
224	My natural supports often make me feel as though I don't need their help, when actually I do. I can use their help to give myself a small break every once in a while.	Apr 19, 2011 1:00 PM
225	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
226	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
227	It is very hard to ask from natural supports-- I feel as if it is a hardship on them to help out esp. for no pay. Asking them to take on a lot of responsibility.	Apr 19, 2011 1:19 PM
228	They don't exist in small town and rural communities	Apr 19, 2011 1:29 PM
229	Friends and family, while having good intentions, are not qualified to care for our child and have shown poor understanding of his disability. After "help" from natural supports, I always feel a bit beat up. I would much rather pay someone.	Apr 19, 2011 1:31 PM
230	Natural supports are not trained professionals and should not be used in place of them but rather in conjunction with them.	Apr 19, 2011 1:50 PM



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

231	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
232	Natural supports to me are ME.. As an older parent of a 22 yr old aging out of school...there is NOTHING out there... Yes Special Olympics, community activities are great but what about employment, job coach, daily living coach ( before I die), quality transportation, therapists & someone to help coordinate it all ?	Apr 19, 2011 3:11 PM
233	I believe we should look to ourselves and our immediate and extended family and friends before looking to the government for support for our unique blessings.	Apr 19, 2011 3:24 PM
234	My natura supports are very imited. My parents will not help at all, they feel that my childs disability is something he could "fix" if only he would try harder. My husbands mother helps occasionally but she is much older and truely no one else helps with my child. I would love to be able to rely on natural supports however, very few are educated on autism or care to take the time to be educated as it does not directly affect them.	Apr 19, 2011 3:27 PM
235	"Natural supports" are a blessing from God. What they do not provide so much that my son so desperately needs is more funding for things that insurance doesn't cover like homeopathic doctors, dietary supplements, professional childcare and certain effective, but costly interventions for children with autism.	Apr 19, 2011 4:11 PM
236	This is a very interesting topic, especially given the aging population. Sometimes the most reliable supports are ones the family has to pay for.	Apr 19, 2011 4:20 PM
237	I receive good emotional support from church, friends, and support groups but very little practical support. Another question you might have asked is, what kinds of support do you receive from "natural supports."	Apr 19, 2011 6:11 PM
238	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
239	We need more information...that is correct from the state...which it seems the state doesn't know...about qualifying...and sooner than later.	Apr 19, 2011 7:23 PM
240	As supportive and lovely as friends and church are, they are not willing to enter in the world of lifting, diaper changes, medication administration, g-tube use, etc. that my son requires. To ask these folks to do so would be more than intrusive - it would be dangerous.	Apr 19, 2011 9:42 PM
241	My 'natural support' is my own mother who is now over 65. She is the only other person who will watch my son with moderate autism. I am a single mom with no other help. I am also disabled and my mother doesn't drive. Natural supports only works with lots of family or if you have money and lots of time to train people.	Apr 19, 2011 10:02 PM
242	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

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

243	Sounds great in theory, but reality is much more difficult to find these "natural supports". This has been true for our entire journey so far.	Apr 19, 2011 11:24 PM
244	Natural supports are busy with jobs, household tasks, personal lives and childcare of their children.	Apr 20, 2011 5:06 AM
245	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
246	It is very hard to find natural supports for a child with behavioral issues. I am lucky to have parents who live VERY close and can help me tremendously. If it wasn't for them my life would be very different.	Apr 20, 2011 8:24 AM
247	i can not stay alone all day by my self	Apr 20, 2011 9:14 AM
248	"Natural supports" vary so widely from case to case and even within time frames that I don't believe that it is possible or fair for policy makers to use this notion as a basis for determining how funding for services is set.	Apr 20, 2011 9:40 AM
249	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
250	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
251	When someone (state workers) tell me that taking care of my child is my duty, I Cry. I need help. I try but get exhausted/sick or need to run errands. Can't. My family is strong, but not always available.	Apr 20, 2011 9:56 AM
252	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
253	My parents deceased,grandparents deceased,brothers deceased,live in rural area,church does not support, then state agency says until I am incapacitated or dead forget about getting any help for a total care person. She is 22 1/2 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
254	"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.**

255	<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
256	families will and/or SHOULD take care of their own	Apr 20, 2011 1:27 PM
257	I think the earlier that you begin educating the community and developing the natural supports that your child the earlier. I think if they connect with your child when they are younger it is more successful.	Apr 20, 2011 2:02 PM

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

258	Natural supports cannot and should not take the place of permanent 24/7 support for my daughter. At some point, I will no longer be able to care for her and there will be no one else who can step in. She also deserves the opportunity to live as independently as possible, but will require support from quality staff to achieve that lifestyle.	Apr 20, 2011 7:15 PM
259	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
260	N/A	Apr 21, 2011 7:28 AM
261	my parents are deceased and my hubands parents are elderly and cannot help.	Apr 21, 2011 8:01 AM
262	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 heppens when I die?	Apr 21, 2011 9:42 AM
263	Our "natural supports" are primarily from involved grandparents. However, they are less able to help as they age and their health declines.	Apr 21, 2011 10:19 AM
264	In real life for most people there really is no such thing as natural supports that are consistintly always available when you need them. It is hard to ask family for help if they are not offering help on their own.	Apr 21, 2011 11:43 AM
265	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
266	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
267	Natural supports would be great, but they can not carry the responsibility, reliability and commitment that is needed to meet our son's unique needs. The person supporting him needs a level of expertise and must take care of his personal care needs, this is not something that we can push onto others that he is trying to have a typical relationship with. He needs supports to have relationships, not relationships based on him being the receiver of supports, that is devaluing and demoralizing. He's been fully included throughout his education and went to his proms with peers, but had an aide to support him, it would not be appropriate to change his personal friendships to watching him like a baby-sitter, or to take him to the bathroom or be responsible to feed him and assist him so he doesn't choke. This was brought this up at his ISP for when we hope he moves onto supported employment, but it would change the quality of his life. It would reduce and limit the skills and accountability of the people needed to support him, "if" we could find people in the first place. We don't have anyone who will spend time supporting him unless they are paid.	Apr 21, 2011 12:53 PM

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

268	Autism requires training and building a relationship;it is different than anything else out there : the lack of dynamic abilities is dishearting and not easy to understand for most "natural caregivers". Its hard to find respite much less professionals. This is a way of the goverment to rid themselves of the "burden" of taking care of our own. Why then pay taxes if its not for the good of the people? I pay school tax, but have no children in school-should I ask parents to find "natural teachers"? This natural implication is a farce.	Apr 21, 2011 1:39 PM
269	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 to find any supports for him beyond his father and myself.	Apr 21, 2011 1:46 PM
270	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

**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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| 271 | <p>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.</p> | Apr 21, 2011 2:26 PM |
| 272 | <p>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.</p>  | Apr 21, 2011 3:00 PM |

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

273	<p>In Oklahoma any supports are very hard to find. private/public Childcare are often times not sensitive to children with disabilities. And financial assistance for therapy and support help is non existent for those parents who work. Unless you have family in town that can help, many parents are having to quit their jobs to care for their children in order to receive financial support from the state. Natural supports are rare. We depend on the public schools, church, and intermediate family. Natural supports, any supports are rare and we just do what we can, which most times are lacking and insufficient.</p>	Apr 21, 2011 3:51 PM
274	<p>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.</p>	Apr 21, 2011 5:04 PM
275	<p>Natural supports are great but my husband &amp; I are the youngest children of older parents &amp; are now providing care for them. We get occasional help to go to weddings/funerals but any not daily/weekly help. We turn down invitations alot because we don't have the support to get out. I envy people who go out to dinner &amp; movies because that is like luxury that we can't do. It is true that the higher the needs of the child/more severe the challenge, the more difficult it is to get help. Especially, if there are any medical needs. Parent caregivers- a truly underserved population.</p>	Apr 21, 2011 5:15 PM
276	<p>My son is now 20 with high functioning autism. After becoming a single parent when he was four, I had to develop a strong network of support for him. A good example of one of his natural supports now is that he had an internship last school year. When summer came, they asked him to stay on. Since he had no transportation, he asked a co-worker if he could carpool and gave her money weekly for gas. And they liked him so much they extended his job through this school year too.</p>	Apr 21, 2011 5:30 PM
277	<p>I am not sure what natural support can, or are supposed, do to help me and my family</p>	Apr 21, 2011 6:32 PM
278	<p>I moved to Central PA before my son was diagnosed. We have no family and very few friends around who understand my son's autism. Finding help has been a severe challenge.</p>	Apr 21, 2011 6:34 PM
279	<p>Both my husband and myself work full time. Our son goes to school full time. We thankful for employers who allow us to alter our work hours for before and after school so that we don't have to rely on anyone unless we are held up. We have one close friend who can help if we need and occasionally my father's father...other than that, we don't want to burrdon anyone or ask for help. I have tried to search for child care for summer care, but I usually end up using a responsible teenager to come to our home.</p>	Apr 21, 2011 6:52 PM

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

280	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
281	as we've aged, the supports have dwindled. We need to work more to deal with increased costs of living and the college expenses from other children, vehicle and home costs - and more. We rarely get time for respite an evening out costs for a sitter --- in excess of \$100 commonly since my child weighs over 200 lbs. and can be aggressive. Natural supports? hah hah my parents and inlaws are in their 80's, my other children's educations and jobs took them 100's of miles away, I do not participate in organized religion any longer - the remaining congregants are older; and the disability support groups focus on families with youngsters. My own health is failing. If there is an expectation that natural supports exist that will fill in when funding fails --- it is a fantasy. I know of no instance of people with post high school aged children who have reliable natural supports.	Apr 21, 2011 8:16 PM
282	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
283	I have to carefully consider when I ask family for help, because it comes with a price of their feeling entitled to be critical and give opinions. I also have to wait until I'm really desperate to ask for help, because otherwise, I am made to feel guilty for asking.	Apr 21, 2011 9:37 PM
284	Natural support is only from his grandmother; however, it is unrealistic to think that she will always be there or is always available. His brother lives in a different state. My sister has health issues of her own, my niece and nephew are heading off to college and his brother has been the only other natural support prior to moving. Natural support is not guaranteed and may not be consistent.	Apr 21, 2011 11:30 PM
285	most "natural Supports" are not qualified to care for our daughter.	Apr 22, 2011 12:29 AM
286	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
287	Family lives far away but is supportive. Friends and neighbors are supportive too but are very busy with own lives.	Apr 22, 2011 7:59 AM
288	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
289	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 financially support me and my son. He has had 17 different paid providers in the past seven years. The systems that exist for services are dysfunctional, 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



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

290	The idea of "natural supports" is great if you have accessibility 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
291	Natural Supports is a term that the government has come up with. Outside family members have no responsibility to help care for children with disabilities.	Apr 22, 2011 11:26 AM
292	the current natural supports are going off to college and are aging. They have provided backup and emergency coverage when needed. Other "natural" supports become un-natural when used repeatedly and with intensity.	Apr 22, 2011 11:42 AM
293	My older, nondisabled daughter, who lives with us, helps out occasionally, but not all that often. She has begun working in a full-time, professional career, and often brings work home with her at the end of a long day. In her free time, she sees her friends. I do 99 percent of all the caregiving which my disabled daughter needs. I am getting tired!	Apr 22, 2011 1:51 PM
294	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
295	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
296	People like to help other people, but don't realize how much we need, but their time/effort/support is not unlimited either. It is unrealistic for me to expect natural supports to make major changes in my two sons (with profound and difficult disabilites) lives.	Apr 22, 2011 8:52 PM
297	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
298	we do not want to have to depend 24/7 on our "natural supports". they love our son but we do not and cannot expect them to care for him over their own families. Grandparents are getting old and will not be a source of support for much longer.	Apr 23, 2011 8:23 AM
299	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

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

300	As stated, communicating specific needs to the right person helps to provide the support when needed. We have some support friends with transportation, some supports for snow day sitters, others at church for the youth group/class sessions, and then the paid supports with wrap services, waiver with home and community supports for activities, and respite thru MHMR. We feel very fortunate to have all those willing to assist, and are very aware and thankful of each person's sacrifices. Communication is crucial.	Apr 24, 2011 6:48 AM
301	My late husband and I never took credit for our son's natural supports. We were always convinced that they were serendipity and also due to the natural good heartedness and caring of these families as well as our son's loving nature and personality.	Apr 24, 2011 10:53 AM
302	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
303	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
304	I am a 58 year old single parent of a young man with Autism. There are no natural supports. My immediate family has no training to care for my son. Very little such training is even available. The only training would come from me. Training for non-natural supports is not out there either. It is ridiculous to think that "natural supports" is the answer as opposed to proffesional service providers. Some families simply don't have that kind of network or resources. Some families have aged out, and the parents are beginnig to need supports as well as their child.	Apr 25, 2011 10:34 AM