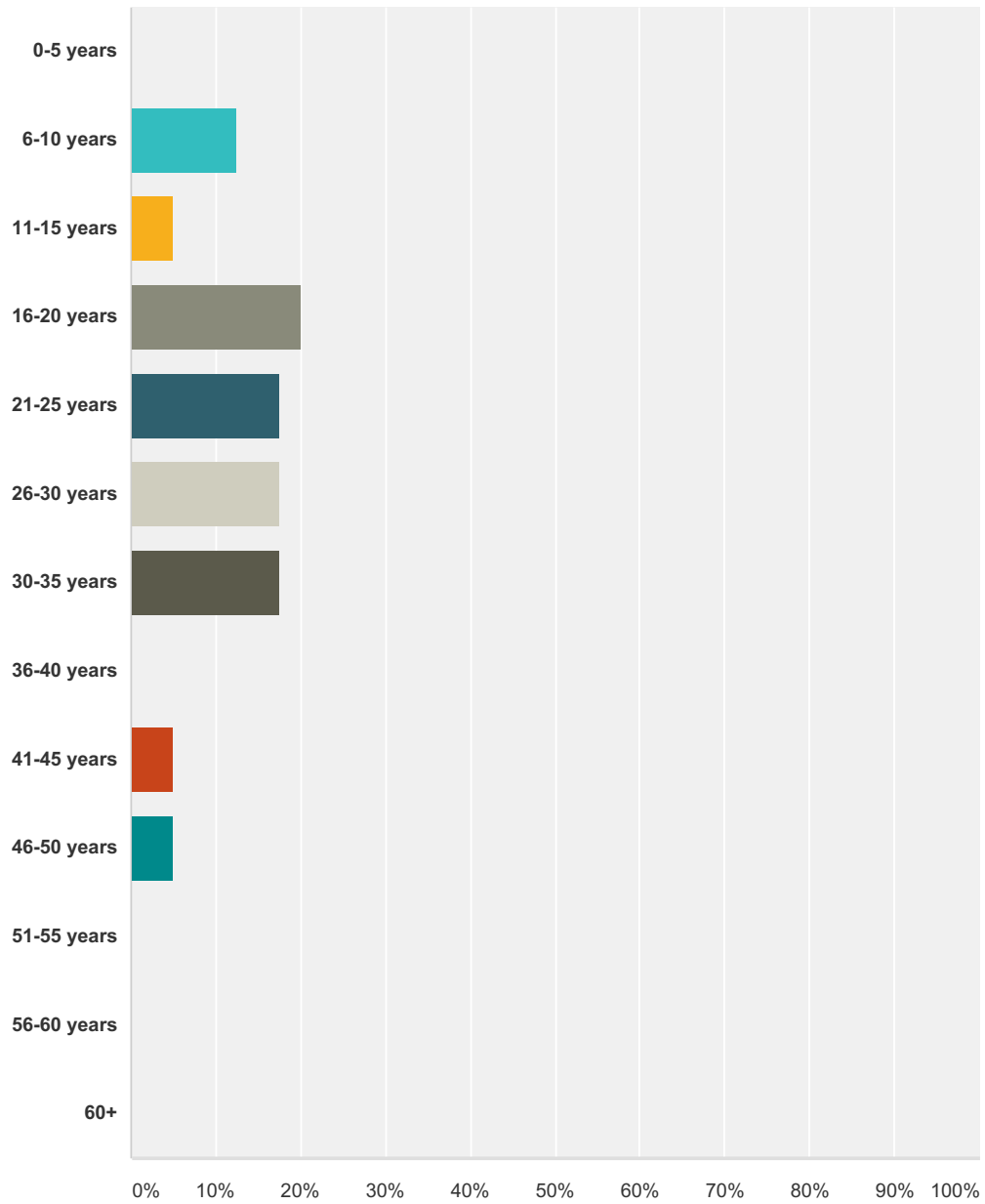


Q1 Age of my child/Adult child

Answered: 40 Skipped: 0

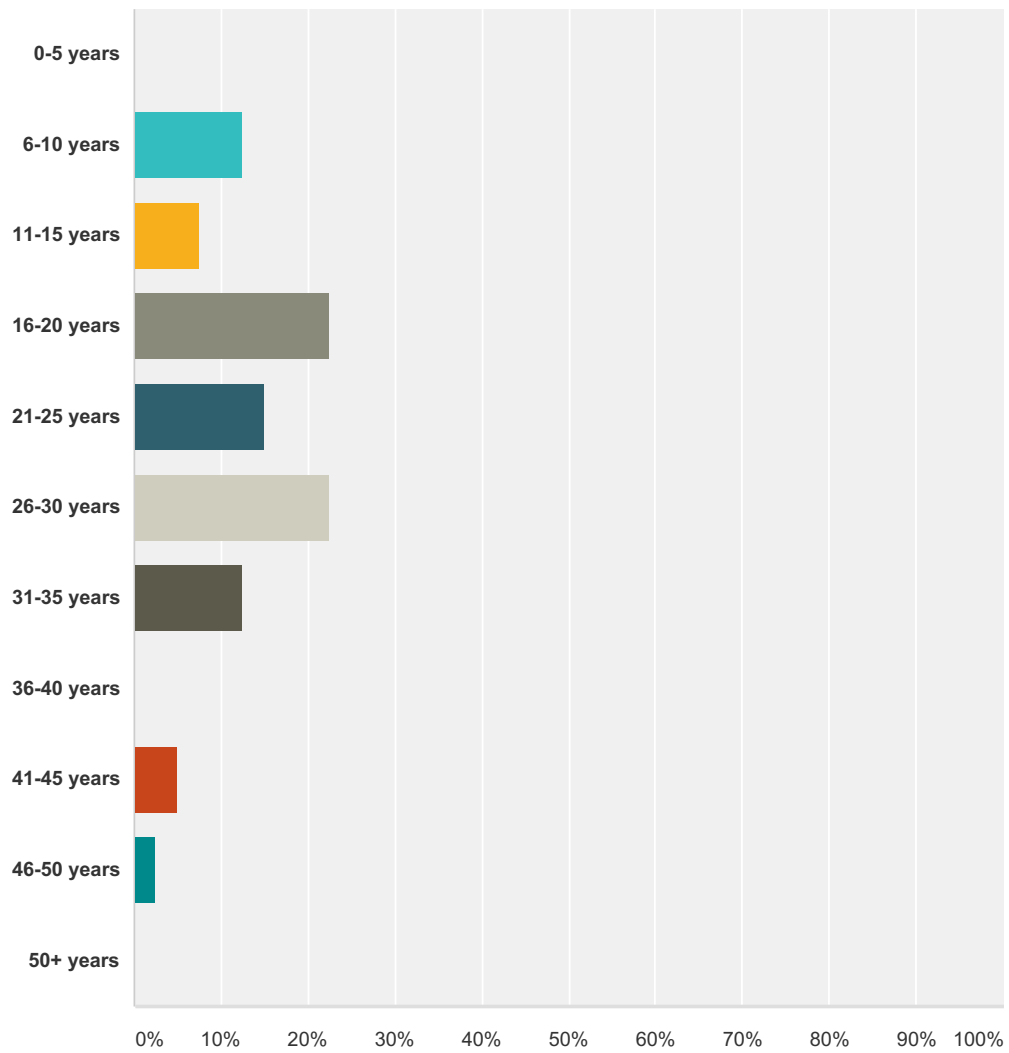


Answer Choices	Responses
0-5 years	0.00% 0
6-10 years	12.50% 5
11-15 years	5.00% 2
16-20 years	20.00% 8
21-25 years	17.50% 7

26-30 years	17.50%	7
30-35 years	17.50%	7
36-40 years	0.00%	0
41-45 years	5.00%	2
46-50 years	5.00%	2
51-55 years	0.00%	0
56-60 years	0.00%	0
60+	0.00%	0
Total		40

Q2 I have been giving physical care to a child or adult child for this many years:

Answered: 40 Skipped: 0

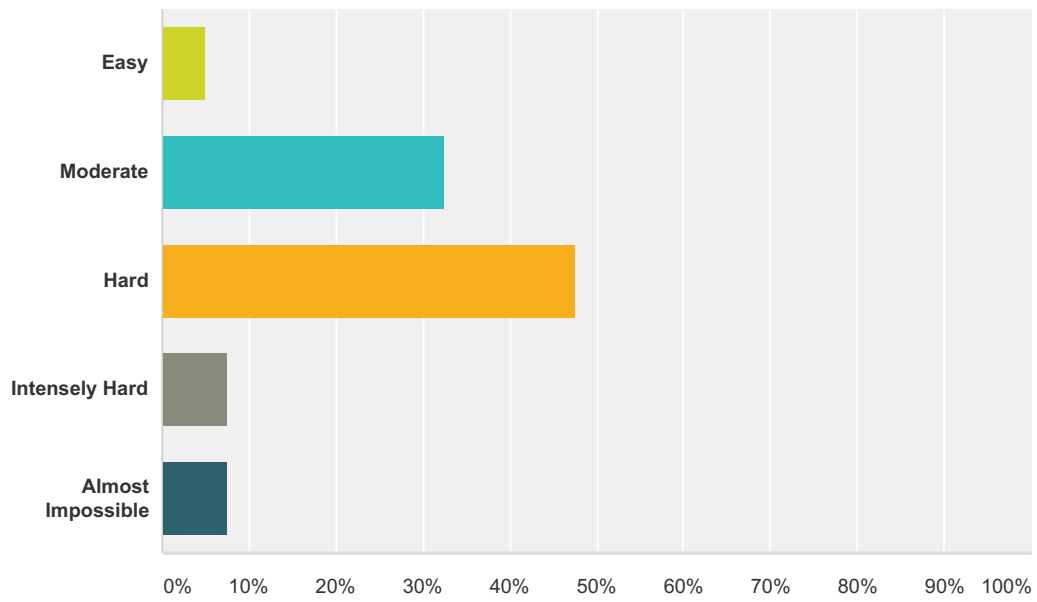


Answer Choices	Responses
0-5 years	0.00% 0
6-10 years	12.50% 5
11-15 years	7.50% 3
16-20 years	22.50% 9
21-25 years	15.00% 6
26-30 years	22.50% 9
31-35 years	12.50% 5
36-40 years	0.00% 0

41-45 years	5.00%	2
46-50 years	2.50%	1
50+ years	0.00%	0
Total		40

Q3 I would characterize the physical component of this caregiving as:

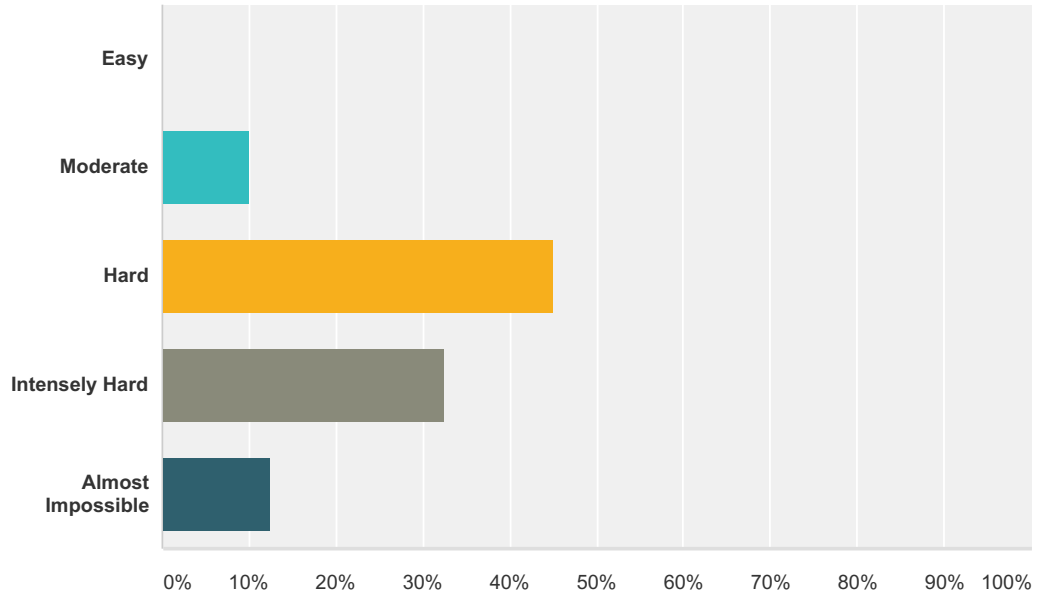
Answered: 40 Skipped: 0



Answer Choices	Responses	
Easy	5.00%	2
Moderate	32.50%	13
Hard	47.50%	19
Intensely Hard	7.50%	3
Almost Impossible	7.50%	3
Total		40

Q4 I would characterize the emotional/mental component of this care as:

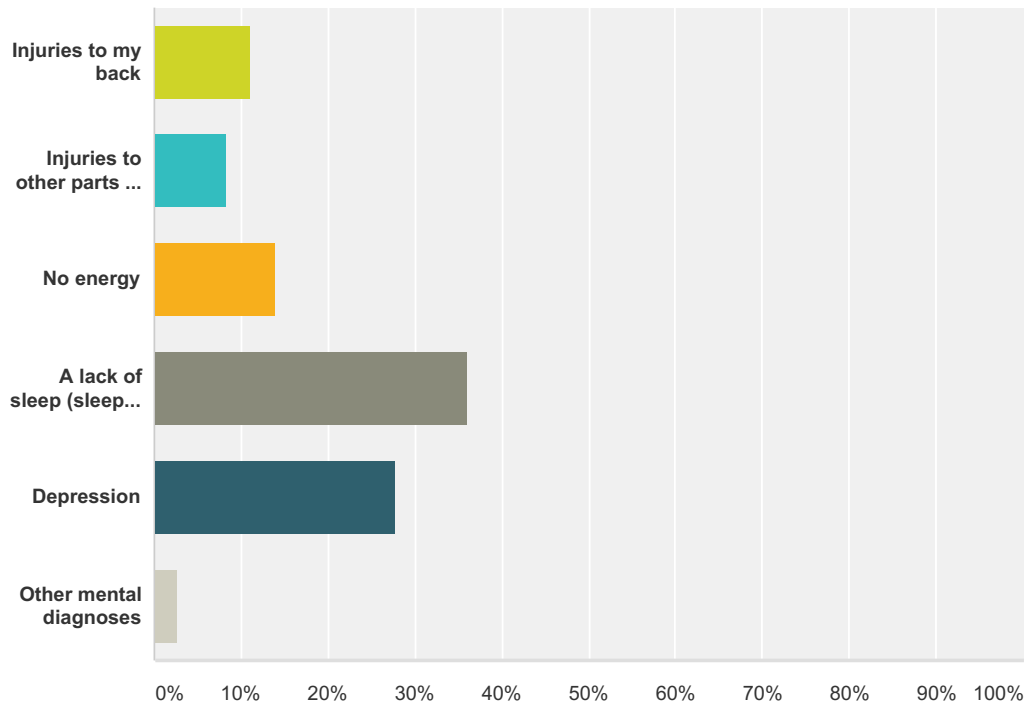
Answered: 40 Skipped: 0



Answer Choices	Responses
Easy	0.00% 0
Moderate	10.00% 4
Hard	45.00% 18
Intensely Hard	32.50% 13
Almost Impossible	12.50% 5
Total	40

Q5 As a result of this care, I have

Answered: 36 Skipped: 4



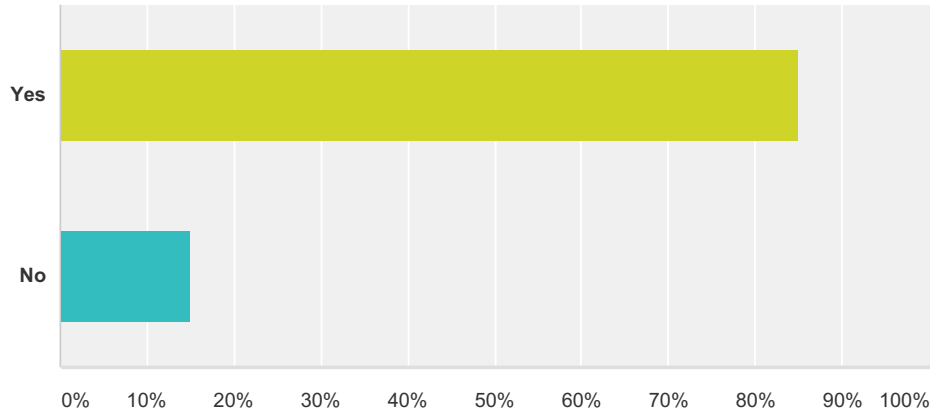
Answer Choices	Responses	Count
Injuries to my back	11.11%	4
Injuries to other parts of my body	8.33%	3
No energy	13.89%	5
A lack of sleep (sleep deprivation)	36.11%	13
Depression	27.78%	10
Other mental diagnoses	2.78%	1
Total		36

#	Other injuries or conditions (please comment)	Date
1	sleep deprivation	2/18/2015 4:26 PM
2	I could have chosen quite a few on number 5.	2/6/2015 5:21 PM
3	In addition, injuries to my neck and arms; depression, previous chronic sleep deprivation.	2/5/2015 9:50 PM
4	Need to be able to select most if not all in the list above!!	2/5/2015 7:39 PM
5	Survey only allowed me to check one box, but I would also say injuries to my back and depression and most importantly I have high blood pressure that my doctor attributes to my caregiving responsibilities	2/5/2015 6:53 PM
6	Couldn't select more than one item so am listing them here: back injuries that reoccur, injuries to other parts of body (arms, wrists, neck, knees, feet), lack of sleep, depression infrequently, loneliness, bitterness, very high stress, poor health habits (diet and exercise), and no personal life of my own.	2/5/2015 6:16 PM

7	Depression, anxiety, metabolic issues due to a lack of exercise (because of no time available)_	2/5/2015 2:09 PM
8	It won't let me pick more than one, but there are injuries to my back, wrists and of course, depression.	2/5/2015 12:19 PM
9	No energy and injury to back	2/5/2015 12:14 PM
10	Injuries to knees, feet, wrists from lifting for transfers. No energy due to lack of sleep as I am up much of the night. Leukemia, which is likely the result of the stress and lack of sleep.	2/5/2015 9:59 AM
11	diabetes type II	2/5/2015 7:19 AM
12	All of the above except other mental diagnoses. Depression is situational if we are going through something really tough with my son.	2/5/2015 7:17 AM
13	anxiety	2/5/2015 12:36 AM
14	Depression in addition to back injury.	2/4/2015 10:56 PM
15	No energy, Anxiety, Depression	2/4/2015 10:04 PM
16	I have had injuries to my arm, elbow as a result of lifting my son from the floor repeatedly.	2/4/2015 9:43 PM
17	I'd like select no energy, lack of sleep, injury to shoulders, and depression.	2/4/2015 9:27 PM
18	Stressed more by the organizations that are suppose to help than by dealing with my child's condition.	2/4/2015 9:22 PM
19	Not much time to myself or adult time with spouse.	2/4/2015 9:07 PM
20	You should be able to check more than one	2/4/2015 8:42 PM
21	Also back injuries and mood swings	2/4/2015 8:05 PM
22	had carpel tunnel surgery due to unusual spoon-holding, feeding position for so long a time. Have arthritis in hips and knees from years of unusual leg positioning over wheelchair back and front wheels in order ot feed from the side of the wheelchair, so he could enjoy seeing TV straight ahead. I learned tricks to resolve back pain/strain and needed to be constantly vigilant about not twisting or turning my torso while carrying an 80 lb person around the house. Whew!	2/4/2015 7:55 PM

Q6 I have help from the "System" - HCBS Waiver, Nursing, Medicaid State Program or the like

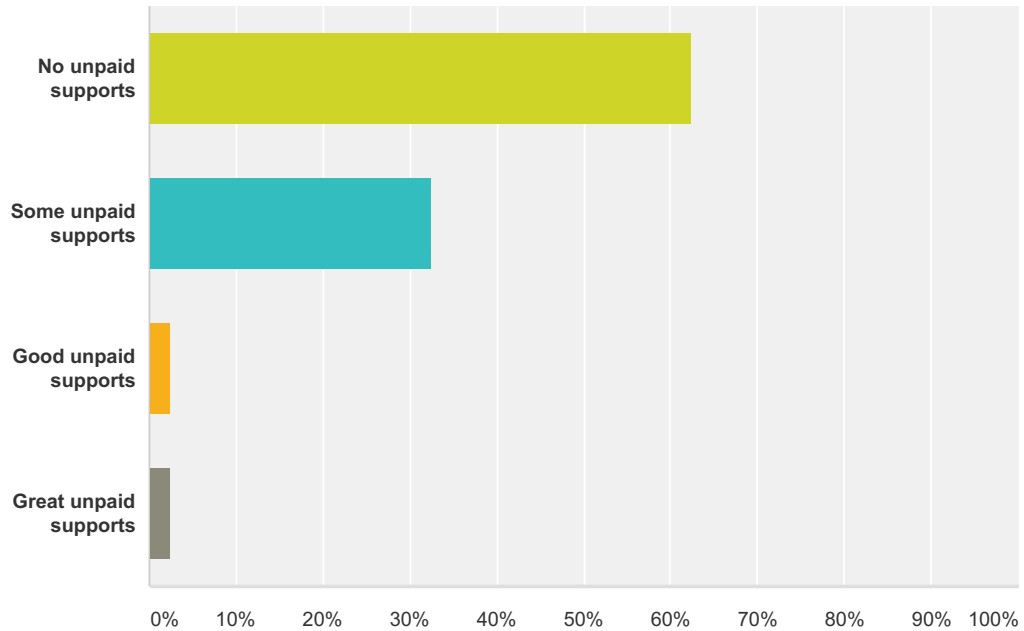
Answered: 40 Skipped: 0



Answer Choices	Responses	Count
Yes	85.00%	34
No	15.00%	6
Total		40

Q7 I have good "Unpaid Supports" to help me and thereby reduce my injuries/conditions (Friend, neighbor, relative, volunteer, etc.)

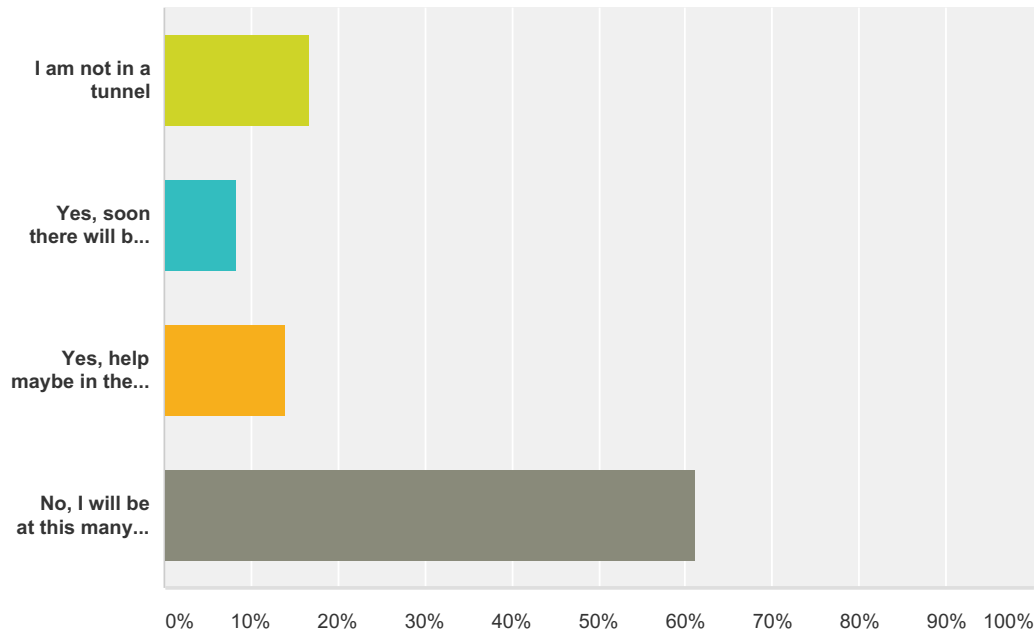
Answered: 40 Skipped: 0



Answer Choices	Responses	Count
No unpaid supports	62.50%	25
Some unpaid supports	32.50%	13
Good unpaid supports	2.50%	1
Great unpaid supports	2.50%	1
Total		40

Q8 I see some light at the end of the tunnel

Answered: 36 Skipped: 4



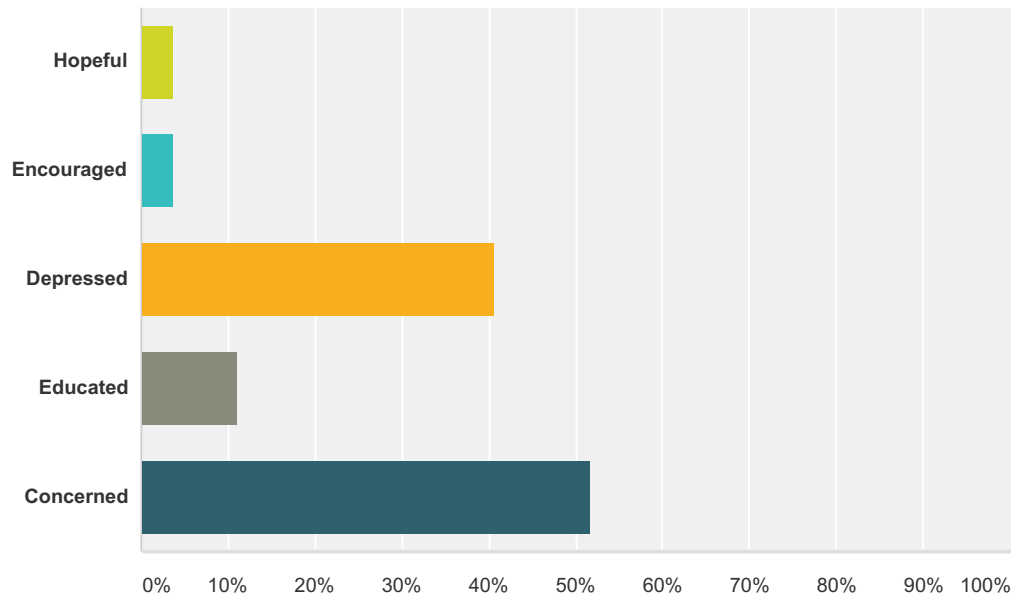
Answer Choices	Responses
I am not in a tunnel	16.67% 6
Yes, soon there will be more help	8.33% 3
Yes, help maybe in the distant future	13.89% 5
No, I will be at this many, many years, no help in sight	61.11% 22
Total	36

#	Other (please specify)	Date
1	We are in our mid seventies, and although my son is in a Host Home, the challenges keep coming including criminal neglect, qay program quitting without notice, etc.	2/18/2015 4:26 PM
2	Not only is there no light, there is no comfort that her care would be of the quality that she deserves.	2/5/2015 9:50 PM
3	Disconcerting question. We have been working with the ARC and provider agencies to try to find a way to provide for my daughter's needs, when I am gone. Changes in Medicaid are blocking us. Recently granted a Comp slot. Number crunching shows that Comp (which they no longer are allowing CNA services with) is actually less, in our case. SLS is painfully inadequate. I am providing care, today, with a stress fracture in my foot and tendonitis in my wrist. I am the default provider when others cancel. Light at the end of the tunnel for my daughter? I pray so. Meanwhile, we are all working to put supports in place before it's too late.	2/5/2015 9:59 AM
4	My time to continue is limited due to my age. Thus, my anxiety about the future	2/5/2015 12:36 AM
5	Even now that my childrens are residing in Host Homes, overseeing their needs is ongoing and never ending and never will be.	2/4/2015 10:04 PM
6	Not sure of time line.	2/4/2015 9:07 PM

7	My son got SLS supports of 12 hours per week at age 22 = fewer hours with necessary, high paid staff to do the care adequately., At 33 he got Comp so I only did care when I took him to a family event, altho the caregiver was available to take him to that event. We just chose to not have the caregiver there for more family privacy a few times per year.	2/4/2015 7:55 PM
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Q9 After taking this survey, I feel

Answered: 27 Skipped: 13



Answer Choices	Responses
Hopeful	3.70% 1
Encouraged	3.70% 1
Depressed	40.74% 11
Educated	11.11% 3
Concerned	51.85% 14
Total Respondents: 27	

#	Other (please specify)	Date
1	the same	2/6/2015 5:21 PM
2	Nothing.....because....the future still looks as bleak as it did 5 minutes ago!	2/5/2015 9:50 PM
3	I do not see help in the near future, just more competition for disability resources with aging baby boomers (myself included)	2/5/2015 7:39 PM
4	Resigned	2/5/2015 4:35 PM
5	hopeless	2/5/2015 2:09 PM
6	flat. This is our life and I must just keep plugging away and try to stay as injury free and sane as possible.	2/5/2015 12:19 PM
7	?????	2/5/2015 12:14 PM
8	ambivalent	2/5/2015 9:27 AM
9	No change. I know our situation.	2/5/2015 7:17 AM
10	Angry that it's even necessary to do a survey!	2/5/2015 12:36 AM

11	Depressed yet hopeful SOMEONE will recognize how exhausting caring for an adult child with a developmental disability IS	2/4/2015 10:04 PM
12	the same	2/4/2015 9:22 PM
13	Skeptical anyone cares beyond making money off my kid	2/4/2015 8:05 PM
14	Concerned and depressed for those who continue to do so much caregiving due to lack of qualified caregivers and adequate funding. My son died, possibly related to lack of adequate care in a specialty setting like the Colorado Regional Centers who are uniquely staffed for overwhelming medical and behavioral needs of people with Developmental Disabilities. No hospital or community care facility have these skills.	2/4/2015 7:55 PM

Q10 Any other comments on health from parent/guardian caregivers? Please forward this link and an explanation to others - listers,, friends, whomever, asking them to participate - <https://www.surveymonkey.com/s/5LG9HYC>

Answered: 19 Skipped: 21

#	Responses	Date
1	I believe health of caregivers of the IDD population is often ignored by the system, yet these folks are the number one warriors of the "system" in providing care. This is self-defeating and poor planning on the part of the "system" and is never included in planning for the future.	2/18/2015 4:26 PM
2	I had a hard time with the "physical" care. For me it isn't so much physical and mental and emotional. Nothing about the amount a patience and skill with dealing with challenging behaviors. This survey did not speak to my experience.	2/9/2015 5:52 PM
3	Health is always an issue. Feel like I have to keep going forever.	2/7/2015 1:33 PM
4	Caregiving changes over time. As some things get easier, others start to loom large.	2/6/2015 5:21 PM
5	The emotional toll our entire family has faced and continues to face is unhealthy - throwing dollars at the system does not help unless you change the system!	2/5/2015 9:50 PM
6	Those with disabilities need a strong VOICE in Washington - to compete with AARP and other supposed priorities which are recipients of funding.	2/5/2015 7:39 PM
7	All care falls on my husband and I, no help from anyone else at all. We may get a free day when our son goes to camp for 4 days a year.	2/5/2015 4:35 PM
8	Even on days when there is help, my time is spent replying to emails from providers, making appointments, following up on equipment repair, ordering or measuring medicines, sterilizing equipment and generally doing things that cannot be fit into CNA hours. This is not a complaint; it is just a fact. I do these things with gladness...it's a joy to be able to have my daughter. Who will provide for her with happiness and joy when I am gone?	2/5/2015 9:59 AM
9	For question 5 I would have answered multiple answers including no energy and lack of sleep	2/5/2015 9:20 AM
10	Caring for an adult child with I/DD and lots of physical issues is physically and mentally exhausting. Getting a break a couple of times a year is nice, but I don't know how long I can keep providing the level of care & support necessary.	2/5/2015 8:54 AM
11	Why does getting services take so much %%%£@ time? I'm talking years. My kids are 9 and everything I read says early intervention is key.	2/5/2015 5:53 AM
12	Caregiving is very debilitating physically, mentally, and emotionally	2/5/2015 12:36 AM
13	I see my unpaid supports dwindling as those people age and are unable to help or are just moving forward to new phases in their lives. I feel there are no new phases for me to look forward to.	2/4/2015 10:56 PM
14	it is difficult o find nurses willing to work at night. It can be difficult to staff the hours we have been given, lack of nurses willing to work when we need the help.	2/4/2015 9:43 PM
15	Why can't the pro-life people help improve the life of my child who is already here?	2/4/2015 9:27 PM
16	Magazine articles tell you that reducing stress is beneficial. One way is to take control of your life. That does not work when your life is controlled by your child's condition.	2/4/2015 9:22 PM
17	One caregiver is an 18 year cancer survivor and another is elderly.	2/4/2015 8:33 PM
18	Lack of support is across all families I know. Where are all the faith based folks who are pro life to help? Where are truly person centered services? Would like others to live the days our families experience. We feel alone	2/4/2015 8:05 PM

19	Needed:: truly qualified caregivers at whatever that would cost!	2/4/2015 7:55 PM
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