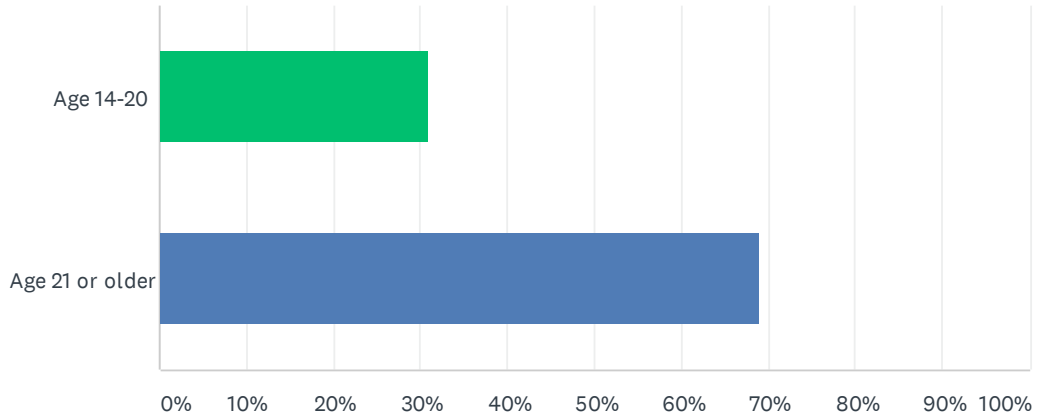


Q1 My son or daughter is:

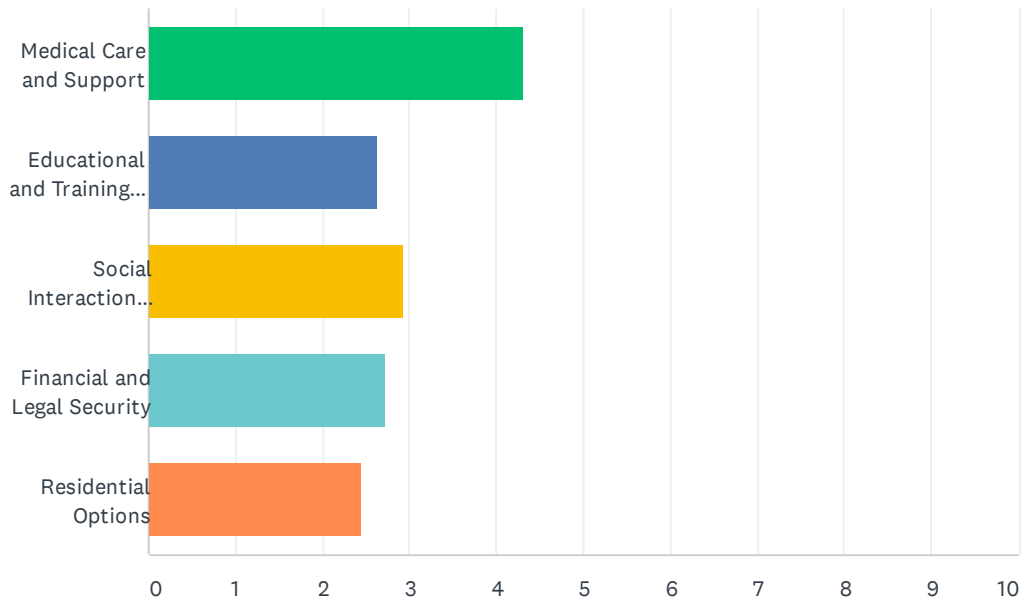
Answered: 55 Skipped: 2



ANSWER CHOICES	RESPONSES
Age 14-20	30.91% 17
Age 21 or older	69.09% 38
TOTAL	55

Q2 Many aspects of life are critical to successfully leading life as an adult with CdLS. While the following topics are all important, please rank these in order of importance to you and your child: (“1” being the MOST IMPORTANT and “5” being the LEAST IMPORTANT)

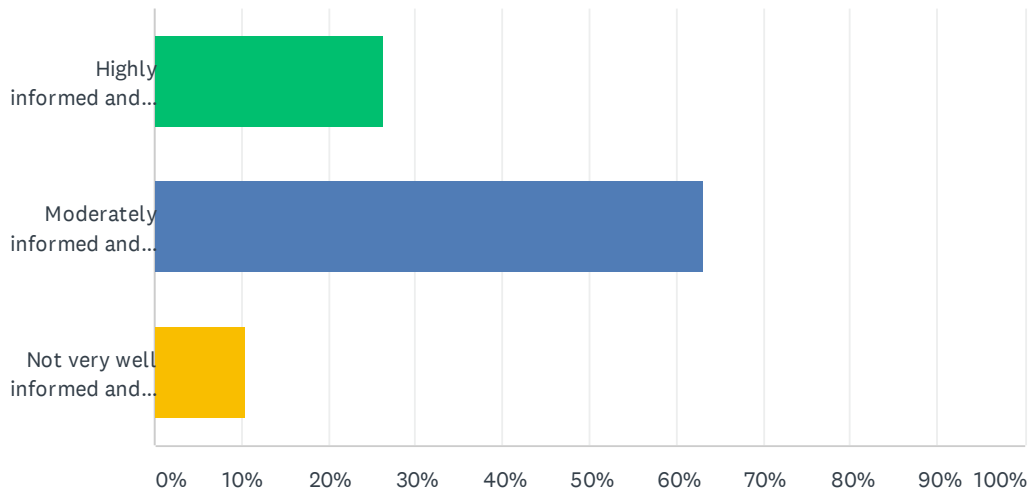
Answered: 57 Skipped: 0



	1	2	3	4	5	TOTAL	SCORE
Medical Care and Support	64.29% 36	14.29% 8	12.50% 7	5.36% 3	3.57% 2	56	4.30
Educational and Training Opportunities	10.71% 6	12.50% 7	28.57% 16	25.00% 14	23.21% 13	56	2.63
Social Interaction with Peers	9.09% 5	25.45% 14	29.09% 16	21.82% 12	14.55% 8	55	2.93
Financial and Legal Security	10.91% 6	20.00% 11	20.00% 11	29.09% 16	20.00% 11	55	2.73
Residential Options	5.36% 3	26.79% 15	12.50% 7	17.86% 10	37.50% 21	56	2.45

Q3 How informed and prepared do you feel you are about your child's teenage or adult years?

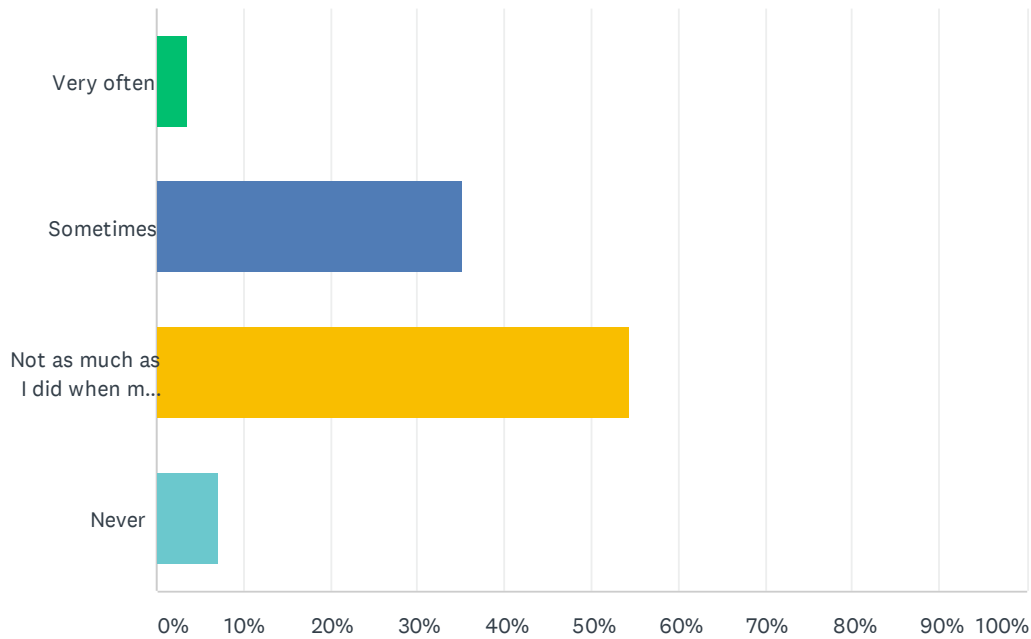
Answered: 57 Skipped: 0



ANSWER CHOICES	RESPONSES	
Highly informed and prepared	26.32%	15
Moderately informed and prepared	63.16%	36
Not very well informed and prepared	10.53%	6
TOTAL		57

Q4 How often do you turn to the CdLS Foundation for information and/or support now that your child is older (either a teenager or adult)?

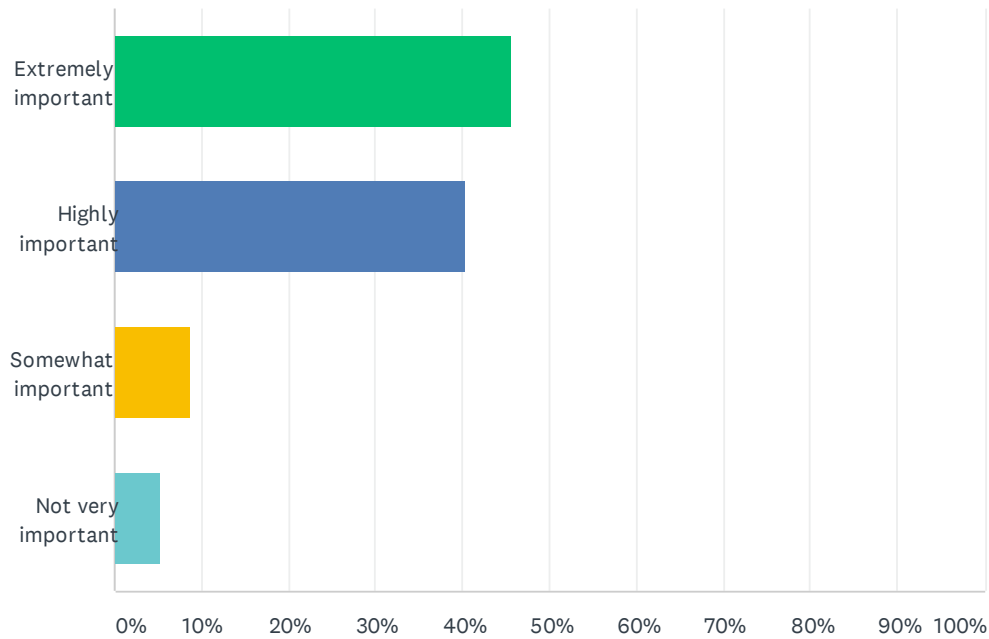
Answered: 57 Skipped: 0



ANSWER CHOICES	RESPONSES	
Very often	3.51%	2
Sometimes	35.09%	20
Not as much as I did when my child was younger	54.39%	31
Never	7.02%	4
TOTAL		57

Q5 How important is it to you that the CdLS Foundation expand its support to families and individuals with CdLS as they transition into adulthood?

Answered: 57 Skipped: 0



ANSWER CHOICES	RESPONSES	
Extremely important	45.61%	26
Highly important	40.35%	23
Somewhat important	8.77%	5
Not very important	5.26%	3
TOTAL		57

Q6 Please tell us how the CdLS Foundation can best serve and support you and your maturing son or daughter today and over the long term:

Answered: 44 Skipped: 13

#	RESPONSES	DATE
1	You are already doing it! Thank you for your support!!	6/2/2020 9:53 AM
2	Connecting us with Doctors and staff that understand CdLS in our area.	5/29/2020 11:58 AM
3	Like the support via conferences (on Zoom).	5/27/2020 10:09 PM
4	I would like to see more information about other families or new medication information on SMC1A.	5/27/2020 9:59 AM
5	Being there is the most important thing and having answers to questions or helping us as Parents find those who can help. Thanks for all you do.	5/22/2020 3:09 PM
6	Services completely change as our kids transition into adulthood. I felt like I was starting all over again as I did when she was an infant/toddler. A list of resources in each state that assist special needs adults would be helpful along with what to expect in regards to the changes in services as they become adults.	5/21/2020 5:38 PM
7	So my daughter is 47... and many of hurdles of life are in the past. She is now living in a residence ,her life is stable, her horizons are set, and the future will come having been prepared for...as best we can...financial and legal plan in place. The worst part of disability is that with family not near by and upon my demise, there will be no loving advocate there to help her get thru medical complications or whatever...just staff...that breaks my heart. Everyone talks about the need for socialization, for friendships and circles of support...but the reality is that friendship is a two way street and it takes VERY special people to 'buy in' when the giving is from only their side. I have tried and tried and tried over the years to set in place a circle of support and it simply falls apart. Her sisters love her, but they each live at a distance, each have their families and busy lives and in the fray of living she falls to the bottom of the needs list. So, like all things in life. We do the best we can and what will be, will be.	5/20/2020 11:19 PM
8	We continue to enjoy conferences and the opportunity to meet and share with other parents. Perhaps you could expand the virtual meetings instead of just bi-annually	5/20/2020 3:50 PM
9	Problems that CDLS adults often incur. Resources available for CDLS adults. How to prevent self injury behavior.	5/20/2020 1:02 PM
10	Help figure out how to have an adult child become as independent as possible to survive beyond their parents passing. and live a full life.	5/20/2020 7:54 AM
11	education and research	5/20/2020 7:35 AM
12	More knowledge of behavioral issues and how to help families find solutions for their adult children.	5/20/2020 1:08 AM
13	My daughter is 50 and in an excellent group home. Fortunately, all her needs are being met at this time. I wish everyone could have this peace of mind.	5/19/2020 10:31 PM
14	Webinars on topics like housing options, public services and funding, data on aging CDLS by cognition and physical impairment, online resources	5/19/2020 9:09 PM
15	Challenges that we may face. A source for information.	5/19/2020 7:46 PM
16	Guidance on steps required to apply for guardianship, social security, medical assistance.	5/19/2020 7:03 PM
17	Spending tome on higher functioning adults with severe behavioral and mental illness.	5/19/2020 6:21 PM
18	answering medical questions. ALSO LETTING US KNOW OF NE MEDICAL BREAKTHROUGHS.WERE TO GET IN TOUCH WITH OTHER FAMILIES WITH CDLS	5/19/2020 5:21 PM
19	Just being available when needed	5/19/2020 4:16 PM
20	More information regarding aging (menopause). Behavior and Sleep issues	5/19/2020 3:33 PM
21	More resources or options for families that don't live on the East Coast.	5/19/2020 2:59 PM
22	It is hard to find drs and nutritionists that can serve her as a 50 lbs adult. Extremely difficult trying to get a communication device for her to use in public. Speech therapist are no help trying for 5 years. So support in these areas are key	5/19/2020 2:51 PM
23	Sharing experiences from parents with an adult daughter with CdLS who lives at home and/or	5/19/2020 2:11 PM

	in a residential facility.	
24	Our biggest issue is our son's sporadic aggressive behavior, as that limits his ability to be out in the community and his options for housing. We are working with his doctors for better medication balance, but we suspect this will always be an obstacle. Not sure how CdLS can help, beyond conveying ideas and successes shared by others.	5/19/2020 1:55 PM
25	Providing information about housing options in the community from state to state is important. Information and support about how to prepare our loved ones and other family members for our aging and the challenges that come with the development of our own health concerns and if and when we will no longer be able to care for our loved ones.	5/19/2020 1:42 PM
26	Information on transition out of school and into day programs	5/19/2020 1:22 PM
27	Continue doing the fantastic job! Thank you! Would like to see more family gatherings (New Jersey).	5/19/2020 1:16 PM
28	Letting us know what others kids habits are as they grow up. I have a 13 years old who looks like hes 8. But he has horrible fits at times. And wants to play his little piano all day. Do ther kids do that too? It would be good to know things like that.	5/19/2020 1:07 PM
29	Behavior, social skills, and how to manage when they carry with autism or Asperger too. How to work with breaking routines and obsessions. Especially when diagnosed when teenage	5/19/2020 12:46 PM
30	My son, Dean has changed behaviorally as he's gotten older. He'll be 30 this year and while he's high functioning and has a job, can't be left alone due to his behavior. There are no services available where we live in FL and I can't afford self-pay. There are no state-supported group homes that I would put him in and I can't afford the private ones. I often feel hopeless and look to the CdLS Foundation for support.	5/19/2020 12:37 PM
31	I like the ideas of the webinars that address various needed subjects. The ask a question is an outlet for a concerned parent	5/19/2020 12:35 PM
32	articles on adult opportunities and care	5/19/2020 12:14 PM
33	Help explore aging issues and living options	5/19/2020 12:05 PM
34	Provide easy to access guidance on what to possibly expect medically and maybe provide webinars regarding aging topics such as changes in personalities and moods as they age, health issues that statistically arise and at what age...	5/19/2020 11:57 AM
35	Prognosis in terms of emotional and physical health, residential and programming options, behavioral supports, etc.	5/19/2020 11:51 AM
36	My daughter is in an educational program through the local college that teaches life skills. Mon-Thurs from 8 to 1:30. They do math, reading, cook, balance check books, take field trips, etc. With Covid, they have been doing this online only. I think a similar program, virtual, with patients of similar ages and/or abilities would be beneficial. They could interact, share stories, have some fun and LEARN	5/19/2020 11:47 AM
37	Provide support and education for families regarding mental health issues of their child with CdLS	5/19/2020 11:43 AM
38	Continued adaptation to our ever changing special needs laws.	5/19/2020 11:43 AM
39	We haven't needed to contact the foundation much at all, but knowing they are there with information is a huge relief. Being a storehouse of good, up-to-date info would be #1.	5/19/2020 11:41 AM
40	Johnnie is a mildly affected and is now working as a substitute education aide. I would like to know ways to help her get the assistance she would need to get her certification. Her biggest issue now is anxiety which stems over her feeling capable but others not seeing her as such as well as finding friends and socializing events. Sadly she doesnt feel comfortable around those more seriously affected by their disabilities but doesnt fit into the typical young adults her age either. She still is more childlike and imaginative play is still entertaining to her. Fortunately she fits right in with the elementary students she works with during the school yr but unfortunately that too was cut short this yr related to the virus and has caused more anxiety at this time. Leaving her home for hours while I work and she requires a lot of attention when I do get home.	5/19/2020 11:39 AM
41	Behavioral challenges	5/19/2020 11:39 AM

42	I need info on special needs trust.	5/19/2020 11:37 AM
43	He is 31, severe and profound. The only thing that is constantly a concern is health.	5/19/2020 11:36 AM
44	Abc	5/6/2020 2:36 PM