

DSC2U Feedback

As of September 8, 2021

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
07-SEP-2021 04:52 PM	false		true	Her big toe nails have always been very brittle. Her doctor is not concerned, but I think there is something more to it and would like to find the cause and what could help repair her nails.	true	There is nothing in here that specifically related to Elyse that made a difference for my preparation of her information. But I can see how it could be useful if she had additional medical concerns.	You may want to consider asking questions about whether the child's meals are dairy free and if they are taking supplements. Based on my research along with the guidance of our high risk OBGYN we removed dairy from our diet (and we continue to be dairy free) during my pregnancy and I also increased my intake of specific nutrients including B12 and Methyl folate for cognitive development. Additionally, after weening her from nursing (at 3 years old) we began supplementing her nutritional intake with

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
							vitamins including methyl folate, b12, choline, etc. Just as such nutritional decisions have shown to benefit typical people in fetal cognitive development and ongoing cognitive development I believe it also impacts those with DS- including our daughter's overall health and development.
07-SEP-2021 11:58 AM	false		false		true		
01-SEP-2021 02:41 PM	false		false		true		
31-AUG-2021 12:19 PM	false		true	Timothy receives nutrition through a feeding tube. He is 59 years old.	true		
28-AUG-2021 05:04 PM	false		false		true	This form made me put maggie as a person and her health into a perspective for the long and short term	
25-AUG-2021 01:17 PM	false		false		true		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
24-AUG-2021 02:13 PM	false		true	Getting the COVID booster. We would like information on this and if there is some way to get a recommendation one way or the other for him. We have split our family in 2 and my son and I live 2 hours from home and our youngest children live with my husband their father in a separate home. I thought we would be able to move home after our youngest was able to get his COVID shots as he turns 12 at the end of August, but now we are truly concerned about the Delta variant and that our schools are only SUGGESTING kids wear masks. We have been in seclusion since June of 2020.	false		Filling out this information was hard as there are something I would have like to talk about under some of these topics. While I may have marked "not important now" it actually IS important, but because of our son's cognitive levels he is unable to do this now and not sure how to even process some of the questions. It is not that it isn't important it is more about is he able or could he be taught to do it. Also, he only eats a small variety of foods. He does eat some fruits and some munchie foods, but absolutely no veggies. It was just so black and white and he lives in the grey area.

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
24-AUG-2021 07:15 AM	false		true	VSD repaired; Already at tubes in ears which are still present.	false	We just had her well exam.	Appreciate the ease of multiple choice, but would like to be able to make comments on some of the questions such as history of VSD - this was repaired and she is doing well.
20-AUG-2021 08:37 AM	false		false		true		
14-AUG-2021 04:58 PM	false		false		true		
13-AUG-2021 06:50 PM	false		true	social connections and expressions/pragmatic speech, stomach aches, orthodontic issues, overheating easily outside (in Texas heat)	true	I will know more when I see the results	Looks good. I'm sure it will grow and look forward to seeing the results.
13-AUG-2021 03:36 PM	false		false		true		
11-AUG-2021 11:17 AM	false		true	Constipation and vomiting combined sometimes with a low grade fever. Potty training and constipation especially when on meds that give him explosive diarrhea (I've tried weaning meds and he just backs up)	true		
09-AUG-2021 08:22 PM	false		true	Reflux issues sometimes dry heaves with it GI just changed meds, just want more information about Down Syndrome and reflux issues	true		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
09-AUG-2021 03:33 PM	false		true	1) The shape and size of Jonah's teeth seem strange. I plan to take him to a pediatric dentist, but I'd love any perspective you may have on how best to address and if his adult teeth will also be like this. 2) I've read about the increased risks of neck injury. Is there a test we can do to check if Jonah has this neck instability? Is that why you asked about the neck x-ray? 3) We're using orthotics and now a theratog (for posture) per our PT's recommendation. I'm curious what the latest thinking is on these devices. Poor Jonah seems to be covered head to toe, and I'm not sure they are really helping him.	true	It's difficult to answer this question until I see your recommendations and discuss them with our pediatrician. I'm hopeful we get some new insights and ideas from the process.	
07-AUG-2021 03:59 PM	false		true	educational, repetitive picking of skin, recommendations of supplements	true		
07-AUG-2021 02:37 AM	false		false		true	All relevant issues related to DS addressed	Not sure
06-AUG-2021 08:44 AM	false		false		true		
04-AUG-2021 10:51 PM	false		true	Saber porque le duele el estómago ,porque se da golpes en el estómago como para que le salga gases, inquietudes sobre su conducta, porque vomita después de comer, porque grita e insulta malas palabras en un horario determinado , molestias en la visión, porque le suenan las articulaciones ,porque quiere bañarse a cada momento, se orina y defeca en el cuarto o en su ropa ,aunque sabe donde es el baño, porque quiere la atención constante de la madre a pesar de su edad. Me gustaría saber si hay ayuda sicólogo , y si es realmente necesaria la medicina que toma o si le es eficaz . Puede todo esto causar ansiedad y depresión.	true	Fue útil porque sin duda las preguntas ayudarán a saber que mismo tiene Linda	Ninguno

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
28-JUL-2021 09:15 PM	false		false		true	Useful by specifically outlining common tests and problems children with Down syndrome commonly have and made it easy to remember past tests/ diagnosis	More age appropriate questions
27-JUL-2021 09:04 PM	false		false		true		
27-JUL-2021 06:00 PM	false		false		true		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
22-JUL-2021 03:51 PM	false		true	Jaclyn recently had her gall bladder removed. Could use help with adapting a diet that is optimal for someone living without a gall bladder. She cannot chew foods easily due to a combination of TMJ and low muscle tone so food choices must be soft/easy to chew.	true	Jaclyn is older so we have been through a lot with her so far. Now that she is older I am focused on helping her attain the maximum healthy lifestyle possible- we could use more info on what to be aware of and watch for as she gets older. She is almost 33. Also will ask primary care physician about the pneumonia shot. Not sure if Jaclyn has received that one. Appreciated that question. She did have her COVID vaccine and we always get her a flu shot annually.	Maybe a little more detail. Like-what surgeries she has had already, etc. Would like more choices on the medical section where it says a choice of "non important" Everything is important to us but some skills are not possible for Jaclyn. Like refilling her prescriptions. It is important but certain things she will never do. It's hard enough for me to navigate the refill system sometimes. We do educate her on what she is taking and why all of the time though.
20-JUL-2021 04:26 PM	false		true	struggles with liquid intake via mouth	true		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
17-JUL-2021 12:41 PM	false		true	In the last two and a half weeks Isaac has experienced auditory hallucinations. He did not eat or talk for two days and is slowly coming back to himself. There is a possibility food allergies combined with a middle ear infection played a role in this. Food allergies is a significant topic.	false	We were recommended this website by the UW Waisman Center. Information regarding schizophrenia as well as other medical reasons for mental health issues would be helpful.	
15-JUL-2021 01:01 AM	false		false		true		
12-JUL-2021 01:03 PM	false		false		true	Thanks, we were one of the test families when the project was in development and are excited to see it roll out	We do regular blood work for B, zinc, and hemoglobin and I was surprised not to see those on the list of questions
11-JUL-2021 04:35 PM	false		true	Her gross motor skills are delayed by a foot turning inward sometimes	false		
08-JUL-2021 06:46 PM	false		true	cholesteatoma surgery planned for fall, possible baha to address hearing deficit and we are not sure if the baha (Osia) this is the best path	false		He does not have an upcoming wellness visit, but I was glad to answer the questions.
06-JUL-2021 05:09 PM	false		false		true	Filling out this form helped me build a check list of things to think about prior to his visit with his pediatrician.	
04-JUL-2021 03:48 PM	false		false		true		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
03-JUL-2021 03:26 AM	false		true	She was asked to remove all her teeth and her surgery is scheduled for 8th July. I urgently want to get opinion from Doctor about this problem	true	Please let me know how I can get an appointment with Doctor	No feedback. Good experience
29-JUN-2021 08:46 PM	false		true	We need to find a good neurologist for an adult age 33 and are willing to travel.	true	I don't think it addressed enough neurological concerns other than Alz or shaking.	
23-JUN-2021 04:24 PM	false		true	Really would like a sense of what to expect as he ages	true		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
18-JUN-2021 05:16 PM	false		false		true	Me gusta que las preguntas son bastante específicas sobre situaciones, problemas o enfermedad que afectan a las personas con síndrome de Down y me gusta que abarca todas las áreas de interés (salud, social, educación, independencia, etc.)	Sería bueno que al final de algunas de las preguntas en el cuestionario se incluya un espacio en blanco para agregar cualquier problema único o específico del paciente o inclusive espacio para profundizar o detallar un poco más sobre el asunto. Por ejemplo, Miguel no ha crecido nada en los últimos tres/cuatro años a pesar de tener una buena alimentación y apetito y tener un examen "normal" de tiroides todos los años. En ningún lugar en el cuestionario encontré el espacio apropiado para incluir esta información o inquietud importante para mí.

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
15-JUN-2021 03:36 PM	false		true	Foot health	true	There were less areas of concern or where more information was needed than I expected.	
15-JUN-2021 12:52 PM	false		false		true		
14-JUN-2021 11:59 AM	false		false		true		
12-JUN-2021 03:54 PM	false		true	Sofia has AA instability which was repaired.	true		
13-JUN-2021 10:40 AM	true	a lot	true	yes	false	good	good
08-JUN-2021 06:33 AM	false		true	WILL HAS PERSISTENT REFLUX FOR WHICH HE TAKES MEDICATION AND HAS DONE FOR MANY YEARS-SHOULD WE CONTINUE?	true	SOME OF HIS APPOINTMENTS HAVE BEEN DELAYED DUE TO COVID 19 LIKE HIS DENTIST AND AUDIOLOGY CHECK-THERE WAS NO PLACE TO ENTER THIS INFORMATION.	
03-JUN-2021 05:45 PM	false		false		true		
02-JUN-2021 04:39 PM	true		true		true		
01-JUN-2021 07:47 PM	true		true	Caida de cabello	true		
30-MAY-2021 05:00 PM	false		false		true	Excellent- easy to follow and comprehensive!	
27-MAY-2021 11:34 AM	false		false		true		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
25-MAY-2021 01:43 PM	false		true	Issues on whether his vocal unintelligible chants border on "self talk" or a behavioral or mental issue. What's common self talk?	true		
10-JUN-2021 09:32 AM	false		false		true		
17-MAY-2021 06:39 PM	false		false		true	good to think through our son's medical care.	It's great! Small suggestions, state at the beginning that it can be saved. And, maybe an average time to complete - that always helps me with my to do lists when I know about how much time to reserve. Thanks for this wonderful tool!!!
07-SEP-2021 11:38 AM	false		true	She has occasional sharp nerve pain in her hands and legs. She also has problems with her feet due to pronated ankles.	false	I am organized.	I expected more lab data would be collected and guidance on results would be included. Normal labs for typical people aren't necessarily normal for someone with DS. There is not a single question about supplements or medications taken.
12-MAY-2021 10:29 AM	false		false		true		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
10-MAY-2021 10:38 PM	false		false		true		
10-MAY-2021 02:15 PM	false		false		true	We are at a loss with Everett's behaviors. Feeling frustrated with him putting his hands in his pants constantly after having a BM. Acting poorly at school and home.	
10-MAY-2021 11:57 AM	false		false		true		
04-MAY-2021 07:00 PM	false		true	Alzheimers? Also had aorta repaired, liver disease corrected by weight loss by orbera balloon, NASH, most recent biopsy was normal though.	false	already had all this info. didn't have spaces to fill things in- some options were awkward. ex: she had the heimlich performed on her in Elementary school- but there was no option- went right to "never"	
01-MAY-2021 10:42 PM	false		false		true		
30-APR-2021 02:55 PM	false		false		true		
30-APR-2021 08:29 AM	false		false		true		
22-APR-2021 08:25 PM	false		false		true		
21-APR-2021 03:01 PM	false		false		true		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
16-APR-2021 02:32 PM	false		false		true		
12-APR-2021 11:38 AM	false		true	Yes, TV addictions.	false	I'm already organized in this manner, but appreciate the desire for feedback.	The issue of tv /screens addiction is very prevalent in the special needs community. At all ages, the protection from screen predators, porn and boundaries around screen time should be a part of HEALTH curriculum, in my opinion. I do believe there should be a section on it.
28-JUN-2021 03:32 AM	false		false		true		
07-APR-2021 12:59 PM	false		true	diabetes	false		options to a lot of the questions did not address needs
06-APR-2021 04:38 PM	false		true	Severe foot pronation, bunions & flat feet due to bone deformities. She wears orthotics and toe spacers with wide shoes for comfort & support. She will need surgery in the future. Also, excessive body hair which creates a problem with managing it regularly. Laser hair removal is being considered.	true	Taking the information and putting it into categories is very helpful.	n/a
10-MAY-2021 07:51 AM	false		true		true		
23-APR-2021 05:06 AM	false		true		true		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
23-APR-2021 05:03 AM	false		true		true		
12-APR-2021 08:56 AM	false		true		true		
12-APR-2021 08:37 AM	false		true		true		
12-APR-2021 08:10 AM	false		true		false		
08-APR-2021 10:28 PM	true	Language availability. It takes more than 2hrs to input everything. Japanese is more useful.	true	1. URINATION PRBLEM: He often don't urinate for more than +6 hrs. Sometimes He spend more than 12 hours without urinating if no one guide him to go to the washroom. 2. SPEECH DELAY: He can not speak word even he is 5 years old. His speech skill is delayed if compare to other DS children.	false	It can be useful when my son & I see the doctor 1st time. However this Q&A form can not be documented even I answered many questions.... So I have no way to use it to share his current situation that perfectly following my answer.	
27-MAY-2021 07:59 AM	false		false		true		
16-MAY-2021 08:31 PM	false		true		true		
02-APR-2021 03:48 PM	false		false		true		
10-MAY-2021 07:47 AM	false		true		true		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
01-APR-2021 02:53 PM	false		true	He grabs his head and screams NO over and over. He also has become violent toward his family.	true	We were able to completely address issues Christopher is having.	Christopher is 50 and has a caretaker that does his laundry, cooks his meals, gives him his pills. An option that says THIS IS DONE FOR THE PERSON, would be a nice addition to the choices given during the questionnaire.
31-MAR-2021 02:57 PM	false		true	James has had a multitude of medical issues and one thing that worries me is that he's been on omeprazole for as long as he's been alive. I know this can cause cancer but when we try and take him off of it, he suffers. Would love an alternative.	false	I have a google doc of all of James's medical issues so I have most of this stuff saved already.	
31-MAR-2021 01:59 PM	false		false		true	With his age I am unsure how much he will benefit but am certainly interested in continuing to have him evaluated and for us as his parents to gain knowledge	
31-MAR-2021 10:58 AM	false		true	Feeding difficulties ie feeding therapy	true		
30-MAR-2021 04:14 PM	false		false		true		
29-MAR-2021 11:07 PM	false		false		true		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
29-MAR-2021 10:00 PM	false		false		true	It was useful for caregiver(am younger sister)to identify his aging health problem. We can take care of his health in advance.	I hope this intake is also useful for both doctors ,people with DS and caregivers in Japan, too. We have less information about aging/health problem for people with DS in Japan so that we do not know much about how we handle aging issues properly.
08-APR-2021 11:00 AM	true		false		true		
19-MAR-2021 05:01 PM	true		false		true		Not this form but the sign up process. Since I joined Lumind+ was not supposed to pay for this but was charged anyway. Codes did not work. Many parents are older and not tech savvy so simplicity is important.
29-MAR-2021 01:33 AM	false		false		true		
18-MAR-2021 09:45 PM	false		false		true		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
18-MAR-2021 02:25 PM	false		true	She is pacemaker dependent, Lesions on spleen, cervical spine spondylosis, tracheomalacia (CT scan suggested it), Psychogenetic non-epileptic seizures, small lesion (Meningioma) found in the parietal lobe (wasn't there 2 years ago), hearing loss increase a lot (from 2018 and 2020), OS macular scaring (eye doctor believes the lesion is histoplasmosis), more short of breath	false	I keep a history sheet for her, with diagnoses, current medications, all the physicians that follow her, and a list of surgeries.	For a person with a complex medical history this is to "simple" for another physician to get a better picture, we are struggling with identifying what is going on and how everything is connected. However, it will be difficult to get to know her in one visit.
15-MAR-2021 08:59 PM	false		false		true		
13-MAR-2021 09:56 AM	false		false		true		
11-MAR-2021 09:52 PM	false		true	Lack of attentiveness/focus with (books, certain activities).	true	Checking to see if I'm missing anything.	
10-MAR-2021 02:46 PM	false		true	Rachel has a terrible habit of putting her hands in her pants. She does it in her sleep as well. I have to clean under her fingernails many times a day. She generally does not do this when she can be seen.	false		
10-MAR-2021 02:06 PM	false		false		true		
10-MAR-2021 01:53 PM	false		false		true		
11-MAR-2021 04:16 PM	false		false		true		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
02-MAR-2021 11:28 AM	false		true	she has chronic "leg" pain and has for years but is well past the 10 yo time frame that Dr Skotko talked about things like hip dislocation being an issue. She has severe ankle pronation and wears orthotics. Do we need to pursue the ongoing pain from some DS typical issue? Might there be something that practitioners not familiar with DS need to be prompted to look for?	true	If there is a print out showing all the areas it will be a useful checklist. Also gives me confidence that we are generally not missing anything - all areas have been looked at by her various providers along the way	
01-MAR-2021 05:30 PM	false		false		true		
28-FEB-2021 07:39 PM	false		true	Identification of painful skin condition that local medical community has not been able to resolve. Resources for handling aging issues for older Down Syndrome individual.	true		
24-FEB-2021 02:05 PM	false		true	All of his toe nails are cracked. When he was a baby, it was only his big toe nails, but now all of them are cracked.	true		
23-FEB-2021 06:34 PM	false		false		true		
18-FEB-2021 06:18 PM	true	The first few times the screen would not let me continue. I wrote to DSC2U and they helped me solve the problem. I registered under Lisa's name, but she is one of two family members with DS. Should I edit my profile info to reflect I am her mother/caregiver?	true	Lisa will be 55 in a week. She is experiencing a decline in her mental abilities. We have concerns about how to communicate this with her primary care physician. We have seen a neurologist, but he told us he has no experience with Down Syndrome and dementia. We would like to connect with a provider who does have this specific type of experience. Lisa is a mother. Her son also has Down Syndrome. He is 25. None of this form addresses her needs as a parent.	true		Lisa already lives in her own apartment. She requires considerable support to maintain as she is experiencing symptoms of dementia. The form did not thoroughly address these types of needs.

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
13-FEB-2021 09:40 PM	false		false		false	I am pretty organized with what he needs to do typically already. My big concerns lie more in the doctors who are not familiar with DS and making needed connections to what symptoms might be co-occurring or red flags for other things we need to be looking at. I am hopeful this sight will be valuable for that.	Maybe have a section where they can write in other, after certain things. I also knew he had nystagmus and such, so maybe going in up front and marking known conditions, then not needing to have that area come up again. I was a little confused when asked up front b/c I was thinking, do I mark eye movement when I already know what that is due to.
12-FEB-2021 12:20 PM	false		false		true	Many good questions to think about -- especially for future issues we might experience as Grace get's older.	

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
14-FEB-2021 09:26 AM	false		true	I am concerned for Kwesi's health because since he has been an adult he hasn't been able to receive any blood work. He resist doctors and will not sit still for any vaccination. Kwesi is 45 and need to have blood work done, Im his guardian and would give permission for a sedative but I can't find a doctor that will do it.	true	This is very useful, some of the questions didn't apply to my son so I left them blank, but Im excited to see the results. thank you.	
12-FEB-2021 12:15 AM	false		false		true		
09-FEB-2021 10:15 AM	false		true	Ovarian torsion - Probable, le and Ovarian mass, le This has happen twice with her. Capri has had ongoing ovarian cyst and ZERO doctors will address this. Current solution is having a IUD implanted	true	Frustrating for me as a parent is the lack of programs for Adult Down Syndrome in my area. We have been told about programs in WI however it is limited to urban areas not rural areas. I just do not understand why this is not required to have a program in every county in WI just like it is required by law to have public schools.	I hope DSC2U will provide some guidance for Capri regarding her medical issues and life after high school.

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
09-FEB-2021 09:39 AM	false		true	Right now, I am just worried about his sleep. He has always been a wonderful sleeper. He breathes with his mouth closed while sleeping and doesn't snore. He is teething right now and has three molars coming in and his gums are swollen around the molars. He is drooling constantly. He has been waking up at night. He sits up in the middle of the night. I do hear coughing and he has constant congestion. He moves around quite a bit, too. I just am not sure if this is all normal and typical for teething. Or, is there something more happening. I know that a sleep study is recommended by the age of 4. Not sure when we need to pursue this because I don't want to do it now if it is too early and if it is just restless sleep due to teething. Recommendations? Will be checking with our pediatrician, too. Also, he has had a rash (small red bumps) on his neck and behind his ear. I am assuming it is due to teething, too. Also, if we do a sleep study and he needs help, what would they recommend at his age? (tonsils, adenoids, CPAP, etc.??) What can be done to help at this age?	true	It will help us (my husband and I) and our pediatrician make sure we are checking for everything possible for Ayden in order to keep him healthy and be his BEST.	Much of it doesn't apply to our son, Ayden, simply due to age. Will I be able to continue to use this form and system throughout his life?
08-APR-2021 12:24 AM	false		false		true		
08-SEP-2021 02:27 PM	true		true		false		
31-JAN-2021 02:01 PM	false		false		true		
28-JAN-2021 10:56 PM	false		true	We are most concerned currently with increasing stress, agitation, obstinance	false	I'm not sure how this would help in speaking with her doctor. Hoping for suggestions from you to bring to her.	

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
27-JAN-2021 03:49 PM	false		true	<p>She has a really low heart rate--as low as 38 on one test and Dr. considering a Pacemaker--doing more follow-up soon. Did a sleep study and started on a CPC AP machine a month ago and doing well--didn't tolerate many years ago when tried--the last time got pneumonia from inhaling liquid build up in tube--but this has worked well this time. Heart rate is still low--often mid 40's-50s. O2 levels went as low as 60% I think they said on sleep study. Did a two week heart monitor on heart rate and had many lows--that was before the CPAP.</p> <p>Echocardiogram test was okay from what I understand.</p> <p>debating on the Pacemaker. Pushing more fluids to help heart rate. Has been on a low carb diet which has probably made her diet lower in salt, since spring of 2020 so wondering if that has lowered heart rate--she was seeming to be much slower in response time, not processing things as well--etc. and thinking maybe oncoming Alzheimers disease, or something--plus being off work with COVID and social activities , special olympics, etc all at a standstill--but went in for a physical in Oct. and found heart rate at 40. Hasn't passed out or fainted, but does occasionally get dizzy, light headed. Her hands and feet get very cold and bluish which I feel has to do with the circulation or lack of it. Dr. isn't sure the pacemaker will help so not sure whether to go ahead with it or not.</p>	true		
23-JAN-2021 08:56 PM	false		true	Abby doesn't sleep through the night. She gets up, goes downstairs, has something to drink, comes back to bed. I'd like for her to sleep through the night.	true		
23-JAN-2021 06:05 PM	false		true	How can we help her to make friends and build positive relationships?	false		
23-JAN-2021 03:52 PM	false		true	Arterial Blood clotting; very serious illness occurred twice.	true		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
25-JAN-2021 01:53 PM	false		true	Negotiating COVID 19 with our 12 year old with DS. She is old enough to transmit this virus and be around others who transmit this virus well and we have recently learned she is uniquely at risk because of having DS from more recent studies. We kept her home and online for school the first semester, but have allowed her to go back to school due to the impact of online school on her emotionally with less social interactions and the decreased quality of the education at home. She is thriving in the 6th grade back in school, but in light of this data indicating she is at higher risk for COVID19, have we made the right decision? Should we allow her to stay in school? It's a large school, mask wearing is accepted. She also announced in her first week back, she was trying out for the school musical, which we let her do because it was a virtual audition, but then she made the cast! They are limiting the cast of students to 30, require masks all the time - even when singing, learning choreography on zoom, practicing outdoors when possible, and recording the show to deliver a virtual performance when done. All the right things, but should we let her do this? It is very hard to feel comfortable with the balance of what is needed for her overall development and mental health and also mitigate her risk appropriately in this pandemic. So, guidance for adolescents with DS in this pandemic would be very helpful, yet are incredibly challenging to create I'm sure.	true		The option for a discussion on zoom of the results would be great. I love the simplicity of the format and ability to fill out everything online. I'm just old fashioned enough to miss a conversation with a provider or the DS clinic coordinator to make sure we are on the same page for next steps.
19-JAN-2021 08:19 AM	false		true	Gtube due to non eating or tiring when eating	true		
23-JAN-2021 06:34 AM	true	English is difficult to understand for me	false		true		
16-JAN-2021 04:31 PM	false		false		true		
13-JAN-2021 01:06 PM	false		true	Mental Health is our biggest concern for the last 2 years	true		
13-JAN-2021 12:45 PM	false		true	Mother is blind and needs help to help her son	true	useful	ok

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
12-JAN-2021 08:04 PM	true	I entered my payment info but forgot to enter the coupon code. When I went back to enter the coupon it said it was invalid. So I paid the full \$49.99	false		true	Some questions did not ask whether the symptom or skill was present/not present before she became depressed.	
06-JAN-2021 07:59 AM	false		true	Lack of sleeping/sleeping throughout the night.	true		
05-JAN-2021 01:26 PM	false		true	Tics - thought to be Tourettes.	true		
04-JAN-2021 08:54 AM	false		false		true	I like how easy this was to use and fill out. Just a quick click through was refreshing.	
02-JAN-2021 09:41 AM	false		false		true		
29-DEC-2020 11:48 AM	false		false		true		
03-JAN-2021 01:14 AM	false		true	Ruby has type 1 diabetes	true		
21-DEC-2020 06:48 PM	false		false		true		
26-DEC-2020 10:41 AM	false		false		true	It reminded me to check on her most recent blood work.	

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
17-DEC-2020 07:36 AM	true	not applicable not available and some questions needed to be open ended	false		true	needed more from a developmental perspective for me to share challenges and process such that it could help support other caregivers. FOr adults with DS more options and resources or information needed to be taken in terms of employment, vocational and adult related concerns.	Give a not applicable option
11-DEC-2020 01:38 AM	false		false		true		
10-DEC-2020 05:39 PM	false		true	At 9 months, Mateo is spitting up frequently. He has some constipation so we are interested in dietary advice to help with that.	true		
08-DEC-2020 01:10 PM	false		true	Nathan has persistent sleep issues where he is up anywhere from 2-5 times x night, even on melatonin.	true	The questions provided guidance on what I can be asking his physician and things we need to keep monitoring.	
07-DEC-2020 06:36 AM	false		false		true		
04-DEC-2020 02:22 PM	false		true	Adrenal insufficiency: I didn't see a question that would have elicited that information.	false	Already have a handle it. The form is great...	
03-DEC-2020 06:51 AM	false		false		true		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
24-JAN-2021 10:49 AM	false		false		true		
02-DEC-2020 01:13 PM	false		true	<p>Fiona was diagnosed with POTS (postural orthopedic tachycardia syndrome) in 2012. She was taking floniene, but that was stopped in approx. 2014-15 due to concerns about water retention, sleep problems, and not much benefit.</p> <p>However, I realize now that she is showing a lot of symptoms again, and would like advice on this condition and Down syndrome. POTS runs in the family, and her sister was treated successfully with midodrine. I want to ask Fiona's doctor to try midodrine, but I'm worried about describing and persuading doctors about this condition.</p> <p>I'm also worried about Fiona's executive functioning--she has serious difficulty getting from point A to point B without constant nagging. She resists schedules, etc. It has deteriorated significantly (partially due to the pandemic isolation), but this has been a serious problem for years.</p> <p>Finally, we are trying desperately to use her CPAP, and she is not making progress (refusing to use mask for more than about 1/2 hour at night, keeping herself awake to avoid having to use the mask at all). We have tried trazodone and GABA to get her over the hump, but she had paradoxical reactions.</p> <p>Fiona has a long history of being very oppositional and this is severely impacting her quality of life. She has an excellent psychotherapist and we have worked hard to improve her life skills, but Fiona's quiet oppositional nature and the difficulty in motivating her is truly hampering her life. She is totally intrinsically motivated and it's extremely challenging to get her to think long-term about why she should do something difficult today. I really need help with getting her executive functioning, motivation, and energy level to a consistent level so that she can apply all the good habits of health. Is there something medical that we are missing? If the medical was in place, would the behavioral issues improve? Unless we can treat her severe sleep apnea, I don't think she will ever feel truly healthy.</p>	true		
02-DEC-2020 08:58 AM	false		false		true		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
01-DEC-2020 11:59 AM	false		false		true		
29-NOV-2020 02:02 PM	false		true	Ian has involuntary head movements, from what I can tell it is called tardive dyskinesia? They were caused by a side affect of Buspar that he was taking for anxiety. They lessened in severity with time after taking him off the medication, but are still present. This was about 5 years ago that they started, maybe a little longer. I took him to a neurologist to see if there was anything that could be done. Unfortunately, there was no known solution, at least at the time.	true		
16-NOV-2020 03:10 PM	false		true	chronic complaints about lower belly pain.	false		
11-NOV-2020 12:22 PM	false		false		false	This was very easy.	Can't think of anything now
11-NOV-2020 11:30 AM	true		false		true		
04-NOV-2020 10:02 AM	false		false		true		
02-NOV-2020 04:13 PM	false		false		true		
28-OCT-2020 05:45 AM	false		true	a sound he makes when he has his dinner and is resting - more like a air bubble going in when he is swallowing even his saliva	true	fantastic!	nothing as yet
27-OCT-2020 02:09 PM	false		true	I am concerned Nola has a dual diagnosis of dyslexia that is impacting her ability to read and advance in school. I am struggling to have the school test or support her in this area and there doesn't seem to be much online that I could find that address it.	false		
27-OCT-2020 03:29 PM	false		false		true	I answered everything from memory, however, it made me think about questions for the doctor, etc. thanks	

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
27-OCT-2020 11:07 AM	false		true	Venous insufficiency, varicose veins, lower leg and foot pain	true	Did not ask about major surgical procedures undergone or severe traumas. Any infectious disease or chronic diagnosed issue.	Need an objective statement for each section that focused the user on what type data is required and what is not needed.
21-OCT-2020 04:58 AM	false		false		false	we had this on hand already	You may take examples of what the child can or cannot do to better gauge the requirements
13-OCT-2020 06:24 PM	false		true	Psoriasis, behavioral disorders	false	This was mildly useful but we have most of this covered already	
10-OCT-2020 04:07 PM	false		false		false	This form just gathered basic information that is committed to memory-- so there was nothing to gather. However, after I get the DSC2U recommendations I will learn whether some information that I provided yielded suggestions that I hadn't previously considered, and that Cristina's Primary Care	Several years ago Cristina had bilateral pulmonary embolism after starting oral contraceptives and flying. She takes anticoagulation meds (Xarelto) when we travel. Perhaps that would not generate any additional insights from this assessment instrument (she sees a

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
						Provider might not have considered.	hematologist annually, so we don't think we have any unmet need with respect to this), but it was interesting that there was no place for me to add that information in her health history. It also seems useful from a research standpoint-- yet another young lady with Down syndrome who had blood clots after starting OCP.
09-OCT-2020 11:31 PM	false		false		true		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
05-NOV-2020 08:20 PM	false		false		true	It was useful, but there are some nuances that can't be reflected in yes or no answers such as does she have trouble swallowing pills. She can swallow all but large pills. Or, the questions about being aloof ...she stays in her room more when her young nieces and nephews are here.	See above. Allow for comments below each section. That would help trigger information to ask primary care doctors about. Also add unexplained abdominal pain to the questions
02-OCT-2020 04:29 AM	false		false		true		
28-SEP-2020 12:49 PM	false		false		true		
27-SEP-2020 09:39 AM	false		false		true		
25-SEP-2020 10:26 AM	false		true	Because she is aging, we are concerned about the future onset and progression of Alzheimer's Disease in people with Down Syndrome.	false	We stay on top of all this, and she sees her family practitioner about every three months for bloodwork and a checkup related to medications and osteopenia.	Address more issues of aging in people with Down.

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
20-SEP-2020 04:47 PM	false		true	Experiencing regression on a large scale!!! Need help to treat neuro-inflammation or whatever is causing severe dysfunction.	false	My son is 28 years old. He has a significant medical history and I have been doing this for some time. All that was needed to complete this form is already in my head. The difficulty is arranging and continually updating information for anyone else who may need take my place someday.	Do please leave space to leave further explanation of issues, function and where we have been. And, in my son's particular case, it is very offensive to have indicated his biological (assigned at birth) sex and have him addressed as "she", without being provided opportunity to indicate his gender identity. He is transgender. Please use he/him pronouns. I do very much hope that this issue can be corrected.
16-SEP-2020 10:54 AM	false		true	Tear ducts	true		
17-SEP-2020 05:13 PM	true	I completed the form and hit submit and it didn't work.	false		false		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
15-SEP-2020 12:30 PM	false		true	Ron has been diagnosed with PANDAS	false	I'm already knowledgeable, so this was very easy to complete.	Not sure yet. He has Type 1 diabetes, not type 2, so I'm not sure if that makes a difference for this.
13-SEP-2020 01:47 PM	false		true	Nutrition and vitamin supplements	true		
09-SEP-2020 08:19 PM	false		true	Dysphonia. Unilateral Vestibular Hypofunction. Osteoarthritis. Cervical neck surgery 0+32	false		
09-SEP-2020 05:47 PM	false		true	he seems not to grow. He's smaller than all his peers with Down syndrome	true	This is the very first time that I had to answer such an extensive list of health-related questions. Made me think of some issues.	Lev suffers furunculosis on his buttocks but there was no way to indicate it.
09-SEP-2020 11:39 AM	false		true	Joshua is only 6.5 months old so much of this did not apply, but I am concerned for his sleep. He gets about 9 hours of sleep a night and wakes up very early at around 4-5am. I have read that Children his age should be getting 11-12 hours of sleep at night. He is also very fussy throughout the day, which I'm not sure if it's related to his lack of sleep (quality and quantity).	false		
28-AUG-2020 05:02 PM	false		false		true	It highlighted some things that need to be done but have not been done yet.	
27-AUG-2020 01:15 PM	false		true	More about aging with DS so I don't miss something important to enhance his life	true	Helped me remember area that I need to address with him	

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
26-AUG-2020 06:47 AM	false		true	Bruxism Early morning riser, Persistent cough, borderline thyroid blood test results, testicular self examination	true	The form helped me to focus on Tom's needs	The questions where it asks me to compare my child's growth and abilities with another child with Down syndrome is tricky
23-AUG-2020 04:46 PM	false		false		true		
23-AUG-2020 03:18 PM	false		false		true	I went back in the MyChart and reviewed when his previous tests were done. Some I didn't know needed to be repeated periodically, it's something I can discuss with his doctor.	I don't have any feedback at this time. I might have more questions once I read your report.
19-AUG-2020 01:23 PM	false		false		true		
19-AUG-2020 01:10 PM	false		true	Late diagnosis of autism at age 38. Reactions from respidol and trazadone. Trauma from treatment (eye drops) of severe conjunctivitis and 6 day stay in ER. 8 months later - sepsis from UTI resulting from refusal to take showers at group home resulting in hair loss. One year later, gall bladder removal.	true		
19-AUG-2020 12:19 PM	true		true	Sam is mostly non-communicative with a 5 year old mentality. He needs supervision due to lack of safety understanding, keratoconus and partial hear loss related to chronic ear infections/sinusitis. He is becoming more autistic in behavior though the public school system would never diagnosis him as autistic.	false	note above please	put OTHER for option on your questions
18-AUG-2020 11:22 PM	false		false		true		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
18-AUG-2020 04:22 PM	false		false		true		
17-AUG-2020 09:07 AM	false		true	She has been having tremors in her left hand ice sleeping) (even when sleeping) and in the back of her neck, Her thyroid medication was altered. She feels anxious when this happens. She is 43 y/o and her periods are not regular. Bloodwork shows she is not in pre-menstrual cycle as I had assumed.	true		You have created an amazing, inconclusive document which will help so many of us who have loved ones with Ds. Thank you so much!
16-AUG-2020 04:15 PM	false		true	Andrew has not spoken in over 20 years. He still says grace before dinner. He no longer exercises or cleans himself. Just wants to sit in the chair and talk to himself.	false	Form seems geared to younger people. He can no longer do the things that were asked	
14-AUG-2020 11:29 PM	false		false		true		Clarify that the Primary Care provider is the Medical Provider and not the Parent
12-AUG-2020 09:50 PM	false		true	She has also been diagnosed with Tourette's	true	I was able to give you a brief description of our concerns and you also asked questions that help me think deeper on her condition	
12-AUG-2020 03:38 PM	false		false		true		
12-AUG-2020 09:59 PM	false		false		true		

date_submitted	technical_difficulties	technical_difficulties_memo	missing_concerns	missing_concerns_memo	usefulness	usefulness_memo	suggestions
12-AUG-2020 04:28 AM	false		false		true	This will be helpful for his primary care physician to not forget anything in consultation.	