

“Conscious Discussion” interview, November 13, 2012 (Lillian Brummet)

<http://www.blogtalkradio.com/consciousdiscussions/2012/11/13/raising-a-disabled-child>

Lillian: Hello everyone from around the planet and welcome to our wintery months. Do you guys have snow yet? We had a little whiff of snow that came once and melted away and then yesterday it came down in beautiful, beautiful snowflakes, but it hasn't stuck around yet. We're here in BC, basically, if you look at your map we're right above the Idaho border, where Idaho matches up with BC, Canada. That's about where we are on the map.

We're going to be talking about parenting today, positive parenting: how we can deal with children that have different kinds of challenges, mainly physical disabilities but there are other disabilities out there, including emotional disabilities, mental disabilities, that kind of thing. We're going to be sharing a lot of information on how to manage a disabled child, how we can deal with the other siblings in our family, how we manage the other people in our life, the people we might be encountering who don't have experience with disabled children. What we can do to help their processing of it. And so much more that we're going to be covering today. We have an expert in this regard. In fact, what I'd like to do first is send a shout-out to Richard Kuritz of Strategies PR dot com. He suggested today's guest for our radio show and of course we just had to have Steve in today. There are thousands of parents out there of disabled and challenged children that are really feeling lost. They may be feeling isolated from other people because they're so involved with their child and the child's needs and therapies and what have you, and they feel like they don't have a life, that they've lost connection with themselves. They may feel a little helpless, because maybe they're being told there's nothing that can be done. There's a lot of emotions involved with being the guardian of, teacher of, or parent of disabled or challenged children. So we have our expert, Stephen Gallup, here today and he's going to be helping us through this frightening time. He's going to be sharing information for those of us who haven't *had* experience with disabled and challenged children in any way and all of a sudden one day a family moves into our neighborhood and we're not sure what to say or do. We feel awkward. Now, Steve has had personal experience in parenting a disabled child. He's also the author of *What About the Boy?*, so check that out online, everyone, *What About the Boy?* is his book, and he's considered to be an expert on raising disabled children. That's why he's here today! You can find out more information about Steve at fatherspledge dot com. Steve, it's great to have you on the show today. Thanks for joining us.

Steve: It's a pleasure to be here. Thanks for having me, Lillian.

Lillian: Welcome to November. Do you guys have any snow or cold weather in your area?

Steve: Well, I'm in a place that doesn't get snow. I'm in San Diego. We *are* seeing some chilly weather right now—for us. But I envy you actually. I vacationed in Idaho just a few months ago, last spring. There was snow on the ground at the time, and my whole family wants to go back again.

Lillian: I embrace every single one of our changing seasons, but I gotta love snow so much. My husband got me into snow-shoeing. It's a very low-impact activity and I just love it. So I'm waiting for the snow to fall, and for it to get thick enough.

Steve: Sounds nice.

Lillian: Now, we talked a little bit about the topic of the day, in the intro, and about your book, but what I'd like to do at this point is talk a little bit about Steve. Who are you, outside of your writing, outside of your career, the various hats that you might wear? How would you describe yourself?

Steve: Hmm. I'm pretty much of a family guy. Writing, literature, and family are my main interests. I love music as well but unfortunately I'm not a musician. I encourage my daughter, who's a budding violinist, but –. Let's see, the most obvious side of my personality is that I've always been a careful,

conservative person, in the sense that I'm mindful of how easy it is for things to go off the rails. I try first of all to maintain stability, and only when that is reasonably assured am I willing to try something unusual. I might add that I've found over the years that this is not a guarantee that everything is going to stay on course. We can avoid some bad outcomes by the decisions we make, but in life we're always vulnerable.

And so there's another side to me that *IS* entirely willing, even eager, to do something very unconventional. That tendency kicks in at times when – when there doesn't seem to be much value in continuing to follow the prescribed course, the course that is set out in front of me. This other part of my nature probably accounts for my willingness to take the unusual steps that I write about in my memoir.

Lillian: Very interesting! So, you are right. We do have to consciously plan, and think about what's going to be happening, and how we're going to handle it, and yet we don't know about the challenges and changes that are bound to happen to us. [*Laughs*]

Steve: Indeed. Um, you mentioned in the introduction that families can be following their normal course in life and not expecting anything out of the ordinary and then suddenly wham! you've got a baby who's got significant problems. This can just completely take you by surprise. In my family's case, my wife had previously taught, as a special education teacher. And I had some premedical training. So we thought we were a little bit better equipped to confront the problem than maybe some other people. But believe me, there's no training that can prepare you for these things.

Lillian: Isn't that interesting. I wasn't aware that both your wife and yourself had some education and some experience with children that had some disability. And yet, when you had your child, and that child was diagnosed with a disability, you felt that you were empowered more than others and yet you still had challenges that you had to face. I think that's important to point out because a lot of people feel so helpless, so alone, and hearing your story today I think is going to help a lot of people.

So let's start with the day you found out that your child had been diagnosed with a disability. How did you and your wife—what were the emotions that you ended up going through there?

Steve: Well, Lillian, first of all, part of the problem was that Joseph was not diagnosed. His mom and I could *see* that he had some kind of problem. And we were anxious about him. But – we started out with a great deal of faith in the professionals. We fully expected that somebody was indeed going to provide a diagnosis. And after the problem had been diagnosed, we fully expected that some kind of treatment regimen would be implemented, something that would mitigate the problem, get things under control.

Now, the doctors did run tests of various kinds. And every time they did, we latched our hopes onto that. We looked forward to learning from the test what was going on, so that *treatment* could begin. But they didn't learn anything that really accounted for what we were seeing. There were some unusual results. For example, he had a heart murmur, but it was benign. That really didn't tell us anything. Um, but basically, after having gone through the protocol that they had at their fingertips, they lost interest. Our son did not fit any of the treatment protocols, and so all they knew to say to us was that we needed to find a way of accepting what could not be changed.

And to us, this was not acceptable, especially in view of the fact that we *still* didn't know what we were dealing with. The way we saw it, our little boy didn't ask for these problems. He hadn't done anything to bring them on himself. And we, his parents, were turning out to be his only line of defense! And we felt totally inadequate, because having taught special education for a couple years really was no preparation for this. So, even though we had no particular expertise in child development, we decided we were going to have to rise to the challenge of giving him what he needed.

This, by the way, would be the feedback I have to offer to the medical community: If a patient presents a problem that the patient (or the patient's parents) feel is very urgent, failure on the part of the doctors to

address it adequately means a lot of people will start going elsewhere for medical care. That *may* not be a good thing for anybody, but that does happen.

Lillian: Absolutely. There are a lot of issues when it comes to the medical professionals. They may not have the—I guess the term is bedside manner, to be able to deal with the parents, their emotions, that kind of thing. Did you find that was an issue for you guys, that the empathy, the sympathy, the bedside manner wasn't there for you?

Steve: Some doctors were better at that than others. Um, I'm not sure I needed a whole lot of empathy. I wanted somebody who could tell us what to do. [*Laughs*] But yeah, some of the doctors who appear in the story I wrote are case studies in how not to be. There was a doctor who said, early on, "It's always hard for parents when they discover their child isn't perfect." And we thought, well, *nobody's* perfect. What are we talking about here? This is—we felt like she was belittling the problem.

Lillian: And that can feel really frustrating because for you, the parents and the child as well, it's your *world*. And you want to be, as a parent, in sync to protect that child, to do something for that child, and you're told, well, accept it, there's nothing you can do about it. Then you start feeling kind of helpless. And then, perhaps, the initiative kicks in where you want to start going out and looking for alternative advice, second opinion, third opinion, and you're getting advice from everyone. *Everybody* has an idea about what could be done and how you could be doing it. So let's start first with dealing with the advice from everyone that you come in contact with. They're well-meaning but maybe you're not receptive to it. Maybe it's something you've already tried and you're feeling frustrated with all of this. How do you deal with that, and not lose friends?

Steve: One thing that might be interesting to people who aren't directly involved in this—I often hear people talking about "*Oh, I know a family and their child is WAY behind schedule and they don't seem to be aware of the situation. They're just not talking about it.*" I think, probably, in a case like that, a lot of times the family *is* aware of the situation. They just are having a great deal of trouble acknowledging it to the outside world. This was true of us. My wife and I did not want to tell people, for the first year or more, that we were alarmed about our baby. We did say, *gosh he hasn't crawled yet, gosh it took him forever just to roll over, and he's crying a lot.* But we didn't want to acknowledge that we were extremely alarmed and that we were pursuing this behind the scenes much more energetically than was apparent to them. And I have found, talking to other families who've gone through this, that this is a natural response. People often want to shield their family situation, and shield their child from a judging world, and try to get things right before they formally present their child as a member of society.

Lillian: The judging world out there—and we have a comment here in the chat room where one of our listeners is black and they are also disabled, they were raised by a couple of teachers and as a disabled person they felt that race also played a role in how people dealt with them. As you say, that judging world.

Steve: Yes, that was one of my first instincts. I felt that the world was going to be hard on my child and so I just didn't want to *tell* people that something was wrong, because I was afraid—I should mention, we're talking a lot about the agony that the parents go through, but—my book is titled *What About the Boy?* because I tried to keep the focus on the child, as much as possible. The child often cannot, or the disabled individual cannot speak for himself, and maybe it's presumptuous of us to speak for him. But that child is the one who is going to be most affected by the decisions that are made. The person who is disabled has a lot more skin in the game than the adults do.

Lillian: Absolutely. You go into this situation where, as you said before, there's this trust, this faith in the medical industry. But they tell you they can't do anything for you, you just have to accept what is, and in your situation that wasn't good enough. So, branching out and looking for other resources out there—how do you go about doing that? Because I know that parents are working with a limited budget. They may

not be able to afford every therapy that's out there. And they don't want to waste their time. So what did you go through? What are your suggestions?

Steve: I would prefer not to get into specifics of particular therapies or our experience with interventions. Partly because different kids need different things! But let me say that generally, when we go a doctor, we are trusting that this specialist is going to know what we need, and will be able to explain a course of action to us in a way that enables us to partner with that doctor—or will refer us to someone who's better equipped to do it. But quite often, what happens is that the doctor doesn't know—and doesn't seem to want to admit that he doesn't know. Or, I think, sometimes the doctor may know more than he's saying. If, for example, the doctor is aware of treatments that are not endorsed by the mainstream medical community—treatments that are controversial—in many cases the doctor may be reluctant to say anything about them. Because the doctor may not want to give the impression that he's saying you should do those things. We actually had a pediatrician who volunteered the information that, she said, “there are programs out there for a child like yours,” but she said “I'm not going to discuss them.” Instead, she recommended that we talk to other *parents*, that we get our leads from them. Sounded like an abdication to me. But the issue here is that, in the case of a child who may have developmental issues, time is truly of the essence. If you start an effective intervention early, your chances of a good outcome are much, much *better* than if you wait until the child is older. A parent who is anxious about a small child's status – *needs* a doctor who understands that, someone who understands what's at stake. To this day I continue to hear from parents who complain that the pediatrician seems to be stalling, as if he hopes the problem will somehow go away on its own. And I tell those parents that they probably need to consider finding another doctor.

Now, your question, where should people go. When my child was little, we didn't have the Internet. It was 1985 when he was born. The Internet is a wonderful resource. There is a lot of nonsense on it as well, and you need common sense to weed out the bad and look at the good, but there are search engines, you can get on Yahoo groups, discussion groups. Actually, my own blog, fatherspledge dot com, has an FAQ page that might be helpful. But talking to people, if you get online, on a discussion board with other people—both parents and interested professionals, they could be from anywhere in the world, you could describe what you're dealing with and quite often they can tell you *not only* the things a doctor should be checking for but they can tell you of specialists, not too far from where you live, who you might want to check out. So that would be my first advice to anyone who is stumped.

Lillian: Fantastic advice there, because you're not on your own. You're not helplessly flailing around at many things, not knowing what kind of results you're going to get. This way, you're connecting with other people with very similar situations, and you're gleaning from the very best of their advice. I think that saves a lot of stress and anxiety. I appreciate that you mentioned that. Now, you did talk about how the doctor tells you, *OK, you have these limitations for your child*, and as a parent you think, *That's not good enough, we're gonna do something about this*. But at the same time, a parent eventually is going to have to understand that there *are* some limitations on their chessboard there, that they can't really do anything about. So can you share with our audience on finding that balance, accepting those limitations.

Steve: Well, limitations come in many different forms. For example, I'm older now than I was when I went through this. And if I were in that situation today, I would have the limitation that I personally do not have the energy to *do* everything I did before. I remember back at the time when my wife and I were going full-bore to help our son, we knew people who had similar situations who were *not* going full-bore and we looked down our nose at them. We thought these people were not adequately devoted, dedicated. I no longer feel that way, because I don't know what else people may be up against. They can have all kinds of issues. So, I'm not judgmental at all at this stage. But in terms of coming up against your limitations, or the limitations in your situation, or what you can do, sometimes you don't know what's reasonable until you find out. Because—well, for example, society used to believe that people with Down Syndrome were a lost cause. Parents were often advised – to institutionalize a Downs baby at birth. But I

personally have seen some absolutely breathtaking examples of individuals with Downs who are functioning at a very high level. I'm just so impressed with what I have seen, and it's literally the result of parents who *denied* that advice, rejected that advice, and did what they could to help their kid develop.

So, is a miraculous, wonderful outcome like that in the cards for everybody? Maybe not. Probably not. But I personally think it's preferable to find that out the hard way. There's a very interesting book by Atul Gawande, titled *BETTER*. He's a doctor, a surgeon. He has a chapter in that book in which he talks about the problem of not being able to know in advance what you can do and what you can't, um, in treating a problem, treating a patient. And his conclusion is that, when in doubt, you should try.

Now, if in the end, you do not see the result you were hoping for – and I'll tell you in my family we did not get all of the result we were hoping for—but you have the comfort of knowing that you left no stones unturned. I have that comfort. And it enables me to be more at peace today.

Lillian: Fantastic response there. Now Steve we're going to move into our first break of the day. Everybody, we're going to be right back with our special guest for the day. We have so much more to cover in our one little hour with Steve. Now, for those of you who want to follow up and contact Stephen directly, head on over to fatherspledge dot com, and of course you can find out more about his book. Go online and research the title *What About the Boy?*, by Stephen Gallup. You'll be able to find that publication as well. All right we're going to move straight into that break and we'll be right back.

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Lillian: We're back, everyone, with Stephen Gallup. You can find him at fatherspledge dot com. I'd like to talk here, just backing up a little bit, about the parents themselves. Now, they're going to be going through all kinds of emotions. They're going to be second-guessing their response to whatever situation they're in at that moment in time, each and every day—situations they haven't been prepared for, that they don't have experience with. They may be exhausted. And the sad thing is that the mother may be responding differently than the father, and sometimes conflicts are going to happen. Sometimes that can tear these families apart. I'd like you to touch on this topic for our audience, Steve. What kind of advice do you have for the parents themselves in maintaining their own relationships?

Steve: That's a very good question. Let's see, how can I begin – my book is a memoir, it's not instructional. And as such, it dramatizes the experience that my wife and I had. There were times when we were indeed not on the same page. Perhaps more often than not. But there are lots of challenges that have the potential to throw us off-balance. And having a child, who's got some kind of confusing, chronic problem has got to be high on that list. Some families dealing with disabled kids react badly. I've known some who split up as a result. Now, I don't have any data, but based on personal observation I think they are in the minority. I *think*, based on what I've seen, that the shared determination on the part of the parents to achieve the best possible outcome for the kid they both love might make them more determined to pull together than perhaps a family that's up against some other type of problem. At least, that determination was a factor in my own family's situation.

My observation is that usually families pull together, especially when everybody shares the same objective. If you can get excited about an objective, which is what happened in my family, sure, it can make the family very strong. Because it outweighs anything else that might be working in the other direction.

What do the ministers say when people get married: They say love bears all things, believes all things, hopes all things, endures all things. I'm reciting that not to hold my family up as any kind of model to follow, because I need to hear it as much as anybody else does. But I do believe that a shared goal, and determination, and patience are a big part of what's needed for the family to hold together in a crisis like this. [*Pause*] Is that too general?

Lillian: No, that's good! A good response. I'm also working in the chat room here with one of our listeners, who is making some really good points. They're saying that 80% of minority families end up breaking up, and this includes groups like Asian, Latino, Black. And they said that the White community has a little bit more networking, a little bit more support, and they tend to stay together, I think about 40% more. And I find that quite interesting. We're seeing society evolve so much, where race and culture, being on that social ladder – those don't define us as much as they used to and yet we're still seeing this happen so that when people have these disabilities and extra stresses in their life it makes it very difficult for them. Wanted to touch on that because there are a lot of different kinds of individuals out there. Another comment here is to check out the different centers that are in your area, like the CP centers, the independent living programs, the life support programs, things like that that might be available for you. Great comment. Now, Steve, I also wanted to talk more about the educational strain that parents go through. They're busy in their own lives. They gotta pay the bills. They gotta keep the rest of the family together, other siblings and so on. They're part of their community. They gotta keep up on their own careers. Things like that. Pay their mortgages. And now they have this additional time-management feature where they're going to have to educate themselves about each and every step along the way. That can be stressful for parents as well. Maybe they don't have the head-space for learning at that moment, and yet basically they have to. What kind of advice do you have in regards to keeping up with this ongoing need to become educated, and maybe some of the exhaustion?

Steve: OK. I believe in being good to yourself. In my family's experience, one of the big hurdles was between knowing something and understanding it emotionally, understanding for example not to beat yourself up, emotionally, when you're having trouble reaching an objective. It's one thing to understand that on an intellectual level, and it's another thing to really know on a gut level that it's true. This kind of insight maybe comes to some people more readily than to others. It was hard for us. Understanding these things with your head is only the first step. It takes time – and not only time but time spent in meditation on the situation – to arrive at a point where it all begins to make more sense.

Basically, we're talking about a relationship, between the child and the parents, and we need to think about both sides. On the side of the parent, there's your attitude toward yourself. My wife and I made extraordinary efforts to help our little guy. You might even say we sacrificed a lot of ourselves, in the cause of trying to help him. My feelings on this are complicated. I do think we were right to try what we did. And sometimes accomplishing something important is difficult, it *is* going to take some sacrifice. But in the process we weren't very kind to ourselves. There is potential for a kind of masochism, in which you tell yourself "*i won't be happy until i get this problem solved.*" And the challenge for someone in a situation like that is to find a way of being happy now, even before you see the end result you're hoping for. And one way, I think, of being happy now is through the relationship with the child. When the focus is on the child – and here, let me give an example from my own story. I was *determined* to help my son, in any way I could. And early in the process, that meant I was continually – well – taking him to see different doctors and continually worrying about what kind of therapy was going to make a difference for him. And I'm not suggesting that I was wrong in doing that. But I made the mistake, I think, of seeing my son in terms of a problem that had to be solved. Fortunately, he found a way, when he was about 18 months old, basically to signal to me that – *Hey, Dad, there's a kid here. Your SON is here. Don't forget to be his Daddy.* It's easy to have fun with your child when you've got an apple-cheeked youngster who's saying cute things and so forth. It may not be as easy when the child is rigid or combative or otherwise in distress. But the child is still a child. And I suspect that a child who has problems is in *greater* need of – loving – than another child does. And furthermore – this is my point – I think interacting in that way, providing that loving, is something that the adults need as well. So remembering to love your child is going to make you happier on a day-to-day basis. As well as helping him.

Lillian: Absolutely. Checking back with those positive emotions and not focusing on the negative ones. I think that's a great point. OK, but we want to talk about the exhaustion that parents are often going to feel. Now, parents of *any* child are going to feel exhaustion at some point in their day or at some point in

their week. They know there's support in rejuvenating themselves, taking time out as a couple. That's really important, but I think even more so when you're dealing with challenges like this. Is that not true?

Steve: Yes, that's true for me *today*. I've got to remember to take a break, find some support, that's something we all need.

Lillian: So how do we go about doing this? As parents. Say we're new to this whole parenting thing. We have this disabled or differently abled little child in our home, and we want to take the time to rejuvenate ourselves. Maybe we just really love to go play cards with our favorite girlfriends, for instance. But we are feeling like, *Oh my gosh I can't leave the house, I don't want to leave all the responsibility to someone else*. Maybe they feel guilty about hiring someone, a caregiver during that timeframe. What's your advice?

Steve: My advice might not dovetail with what a lot of people believe. We did try some of these things. Respite care we found – even professionally provided respite care – was not good. Their only concern, their only question when we're handing off our child is how do you work the TV. We come back and find they've raided the refrigerator [*Laughs*] and the child has basically been neglected. I'm not big on respite care. I'm not big on a lot of these things that social or support organizations might recommend. The strength that my wife and I got on a day-to-day basis was primarily the joy of seeing progress, the joy of working toward our son's improvement. And yes, we did need breaks. Um, and we found things. My wife – she thought at one point, *gosh, we're tried so hard and I feel like I'm up against a wall*. And she thought *on a spiritual level there's something I'm supposed to be doing, to help someone else, so help can come to me*. And she remembered a very elderly woman she knew, or had known in the past. She found this lady, who was in a terrible situation, in a retirement home. She had lost all of her possessions. She was just in desperate straits. My wife told me to take care of the kid for a while and she went to town for that woman. She found out that she was a Swiss citizen, she qualified for a pension via the Swiss consulate, and she got her into a better place to live and began visiting with her on weekends. And it was a change in focus for my wife. It was a constructive thing to be doing. And – I'm just mentioning that as an example of something that could change your focus. It was another battle, in a sense, for her. It wasn't relaxation. But – we rest by changing jobs. That's what my dad used to always say. Find something else that has appeal and check that out.

Lillian: Great tip there. Now, we have a couple questions that were sent in to me via instant message and I do want to check them at this point. They're actually related. I'm not sure if they're from the same person or not. It says, "It looks like, first of all, an individual wants to know how to reduce the emotional impact on their child when they are experiencing stresses like dealing with an ambulance, the appointments, the hospital, the therapies, and all these different things. How do they reduce the impact on that differently abled child? The negative impact?"

Steve: Hmm, good question. I have no specific experience with – at least, nothing comes immediately to mind, but I would think of trying to make the child comfortable and assure the child that you are there for her or him and, um, distracting the child with something amusing if that's possible. When someone is in great fear or pain, distractions don't work so well, but it always helps to know that someone is there for you and with you. [*Pause*] That's not a very good answer, but it's all I can come up with at the moment.

Lillian: No, that sounds great. You've gotta provide some kind of comfort and a distraction. It's interesting that you mentioned distraction; just as a side-note, we interviewed, I think it was a year ago, the "Reach a Child" organization, if memory serves correctly. This individual started an organization where they provided different types of books for different ages, for children that were affected by trauma, so when the first response teams – you know the firemen or police or what have you – when they first arrive on a scene and there are children there, they have this backpack full of books for the children. And I thought what a fantastic response to a situation like that. I think distraction is a really good tip. The other question that was addressed to us, they're talking about siblings. So, there are other children in the family.

And we want to make sure that *they* are getting time, they're not feeling that they are not special. Because a lot of the time, especially in very disabled situations, the child that has these disabilities may absorb a heck of a lot of time and resources. The other siblings are going to be thinking What about me? And they may end up developing some psychological problems later on because of that. They're asking if there is some sort of device for these other siblings, and including that that sibling might be dragged back and forth to the hospital. They're not the one being treated, but they have to go, that kind of thing. Advice for that, Steve?

Steve: That is absolutely true. I can think of families I've known where the sibling experienced exactly what you're talking about, being resentful about having to go someplace – sure, definitely. The sibling certainly needs to have some attention, and some time must be budgeted for that person, too. And love. But when the question arises, I think the best thing to tell that child, if he's old enough to reason, is to come up with an analogy. For example, um, if you mash one of your fingers, that's the finger that you're worried about. It doesn't mean you don't love your other fingers. They're *all* important. But of course we've got to take care of this owie that we have on this one. I don't know. You have to put it in terms where they understand while letting them know that they are just as important as anybody else.

Lillian: A very difficult thing for a parent to do when you're already feeling overworked and overstressed and now they have to deal with this. One of the individuals in our chat room is saying you need to treat the nondisabled child with special trips, special outings that are just for them, and make sure that you are not overloading that child with duties for the differently abled child. Because when they get older they're going to resent having those extra responsibilities.

Steve: That's certainly true, but you know this is not just a problem in families where there's a disability, because I can think of a family where one child was born and less than a year later a little sister was born. And the older sister felt that she had been pushed off the pedestal, too early, and for years she resented that. It created problems between her and her sibling. These are perfectly well, normal kids. So I think all families have to grapple with this to some extent, if they have more than one.

Lillian: And for the parent to have an understanding about that. They think *gee whiz I'm doing the best that I can and now you're laying all this guilt on me*. But we have to understand that children are coming from an ego base and everything we do as parents they can only see it from their own perspective. So we have to work to see that everyone has these well-rounded and wholesome emotions as they're growing up. Now we're running quickly out of time here, so what I'd like to do Steve is branch off a little bit. I'd like to have you tell us about your book, *What About the Boy?* Why did you write this book?

Steve: Well I wanted to – I guess I wanted to answer the very questions that we've been talking about today. Here's a rhetorical question. It's not meant to put anyone on the spot. What would you do if you had a little child, a baby, who was obviously in distress? Mine was. A child who cried almost all the time, who gave every indication that he was suffering in some way. And what if, as time passed, it turned out that child was not achieving the usual developmental milestones, such as crawling? You'd be taking that child to the doctor, of course. Anybody would. But what would you do if the doctor didn't help? That situation is what precipitated the chain of events that I write about in *What About the Boy?* Along the way, I discovered a surprising number of families were having very similar experiences. Like my wife and me, they were having a lot of trouble finding guidance. And if they pushed too hard, they were told they needed psychological counseling. And they said, *But we're not the patient. Our child is the patient*. And because of the fact that so many people were having, and are still experiencing this, I decided to write the story. As I mentioned before, the book I ended up writing is not instructional. It's just a story of what we did and observed. But it's offered as a way of showing what can happen when you pursue a given course of action – Specifically, a course of action that has not so many guideposts along the way, so that you have to find your own way.

Lillian: Very interesting. Sounds like a very good read. That's for sure. So, what drew you to the world of writing? Did you have earlier experiences in that field?

Steve: The first thing that drew me to writing was that, early in life I was fortunate in having books that particularly appealed to me. I remember latching on to a copy of *Tarzan of the Apes* when I was in third grade and subsequently devouring every single title by that author, multiple times. Um, of course, not everybody who enjoys reading feels compelled to write, but I think most writers do start out as avid readers. Secondly, as I grew older, I discovered that I like the process, perhaps not so much writing as *rewriting*. No matter what I was writing, I found myself putting a great deal of effort into going over it many, many times, hoping to address every possible way of looking at the subject and trying to express myself as clearly as possible. And I enjoyed doing that more than anything, and I still do. Of course, speaking doesn't give you the same opportunity for revision. After you finish saying something, you may very well think of a better way you could've made your point, or you may realize you forgot altogether to mention [*Laughs*] something important, in fact that may even end up being the case today, with this interview. So it's safe to say that writing attracts me because of the greater control it provides, for clear communication.

Lillian: Fantastic. Well, you know we're so quickly running out of time here, Steve, and I did want to leave you a couple of minutes to be able to share any comment. We've talked about a lot of aspects of being a parent of a differently abled child, and do you have anything that you'd like to pass on to them that we haven't covered, or any advice at all that you'd like to share with our audience today?

Steve: Well, it's safe to say that hardship comes to all of us. Not everybody has a disabled child but we all, I think, encounter trouble in some form. I write posts about this from time to time on my blog, and I encourage folks to stop by and take a look, and interact if they feel so inclined. Um, hardship is inevitable, but misery is optional. And we get ripped off in life, I'd say, when we think about how much farther there is to go, before we get to where we want to be. My advice, in a nutshell, what I've come to see over these many years I've been wrestling with this, is that we've got to *not* see the present as just an arduous or tiresome thing to get past on the way to that golden future. We need to be at peace today, regardless of what we're doing.

Lillian: Great advice, Steve, I sure appreciate your being here today, and all the feedback from our listeners. Thanks again, Steve.

Steve: Oh, I've enjoyed it immensely. You said some interesting things I'm going to ponder.

Lillian: Oh great! That's good to hear. Well, everyone, our very special guest of the day was Stephen Gallup. You can find him at fatherspledge.com. Hopefully you'll have a chance to check that out and you'll learn more about his book, *What About the Boy?*