

**Senior Voice America interview, May 3, 2012 (Evan Gold & Deb Goldman)**

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**Evan:** All righty! It's Thursday, right? Just double-checking, never sure. One day just rolls into the next. . . . Let's get going with today's show. We've got some really pithy stuff. You know, you hear it, you see it—raising a disabled child. We talk about Senior Voice not just being for seniors. We know that we get a lot of listeners that are younger. We get a lot of grandparents that are raising or helping to raise their children's children. Now, overcoming diversity, talking about raising a disabled child, we've got a guest. . . . Let's get started with Stephen Gallup. He's the author of a book, I think it's "A Father's Pledge." How are you today, Stephen?

**Steve:** Well I'm fine. Thank you for having me on.

**Evan:** You're welcome. Do you go by Stephen or Steve?

**Steve:** Steve is fine.

**Evan:** We have a Steve as well. That's why I was asking.

**Steve:** I was talking to him just a moment ago.

**Evan:** No no, that's not our son! *[Laughing]* But Steve is our youngest son.

**Steve:** Oh!

**Evan:** But you have a disabled child, am I correct?

**Steve:** Well, he's an adult now, but yes I do.

**Evan:** And that's what the book, "A Father's Pledge," is about. Am I correct?

**Steve:** The title of the book is actually *What About the Boy?* "A Father's Pledge to His Disabled Son" is the subtitle.

**Evan:** Gotcha.

**Steve:** But it's a memoir, and it describes the experience of bringing him up.

**Evan:** And was this your first child? Or did you have a few?

**Steve:** This was our first child, and when he came along his mother and I didn't feel—even before we knew about a problem he might be having—we didn't have a lot of confidence that we knew what to do.

**Evan:** Right! And it's not really what you expect. There in the delivery room. Right?

**Steve:** Well no, of course. In the delivery room we weren't aware of a problem, but it became evident in the weeks and months that followed.

**Evan:** And may I ask what the disability is that he has?

**Steve:** I wish I could give you a good answer. He happens to have a diagnosis of autism, but it's not a good diagnosis. In other words, it was given to him at age seven, after a lot of other diagnoses had been tried out, and he really isn't classically autistic. I think he has some unidentified genetic error, which resembles autism.

**Evan:** OK. Well, there's a lot of—people are still trying to study and understand the brain. And I know they don't completely understand, by a long shot. I actually have a doctor who is a brain surgeon. He says we just don't know that much about the brain still. So talk about how it changed your life. You know, some of the things you were going through.

**Steve:** Well, three things: First of all, there is something to be said for having a cause—you know, being passionate about something and being determined to make a difference. Whatever the challenge might be. It's mentally satisfying, or at least it is if you believe you're on the track towards being able to make things better. So that's the upside. But in all honesty this is not the sort of experience I would wish for anybody. I cannot begin to describe the heartache that's involved in seeing your kid have roadblocks that prevent him from doing very basic things, that are simply part of living. Things like being able to go places under his own power? Or more importantly, being able to tell you what he wants and needs. My wife and I also found ourselves becoming extremely frustrated with what looked to us like complacency on the part of the majority of the professionals that we turned to for help. And finally, I mustn't forget to try and look at it from the child's point of view. That's why I titled my book: "What About the Boy."

Because you see the child doesn't have much input or control over what's said or done about this. We can easily talk about the *parents'* anxiety. We can, um, talk about the cost to society of having thousands of disabled children being born every year. But the children are the ones who are affected most of all. They have to live with their situation all the time. Disability affects the entire direction their lives can take.

**Evan:** Absolutely.

**Deb:** How much is he aware of his disability? Does he understand, you know, what he's up against?

**Steve:** Well, I think it's fair to say that he does understand quite a bit. The trouble is that he doesn't talk. He did speak a little bit when he was younger, but then he stopped. And there's the assumption people have that when someone doesn't talk that he doesn't understand. That's erroneous in his case. He showed in the past the ability to read, to understand other languages, to do some math. So he does have a lot of intelligence underneath his—his *barrier* that's holding him down. And so what he thinks about that is hard to guess. I think he has reached the conclusion that he's accepted the level he wants to work at, that's it's the course of least resistance.

**Evan:** OK. And so from your experience—obviously, different children can be helped different amounts. It depends on their abilities and how seriously disabled they are. Correct?

**Steve:** Well certainly. But sometimes you don't know what's a reasonable objective until—you find out! Because, as you say, so little is known, still, about the brain and developmental issues, and also because there's often a *huge* difference between one kid and the next. Even if, superficially, they seem to have similar issues. One child may be helped in one way or by a given intervention and the next child may not, and we just don't know enough about individual children, and how their challenges affect them—that's certainly true in my son's case—and even how the various therapies work, when they do work.

**Evan:** It must be very difficult to try and figure out *How hard should I push him? How hard should I encourage her?* You know, what's that line, right? Because we're just not sure, because as you said, *Well, for Billy over here this treatment or this therapy could work but for Bobby over there it doesn't work.* And they're not sure why. But you've got to figure out how much you should do or how much you should push, right?

**Steve:** Yes, and that's a complicated question. When I was going through this, with my son, when we were much younger, I'll confess that I privately looked down my nose at people who didn't try as hard as we did. But as time has passed, I know that if I were in that situation now I would not have the energy, I would not be *able* to do what we did. So I realize that people bring different skills and abilities to the table, and you can't blame them for what they can't do. But having said that, I *do* believe in swinging for the fences. We don't always achieve everything we want, but we aren't likely to achieve *more* than we shoot for. As I said at the outset, taking on a challenge like this, if you think you have a plan that you can believe in, it's a very positive experience.

**Evan:** Right. And how did the medical community—You know what, I'm going to hold that question for just a second. We're going to go to a break, but we'll be back. We're going to talk some more about raising a developmentally disabled child right here on Senior Voice America, 1250 AM WHNC.

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**Evan:** Well, right now we're talking about raising a developmentally disabled child, and here's something you should know. In 2006, one in 110 youngsters were diagnosed with autism. In 2008, it was one in 88. So something is going on, in our society. Maybe they're doing a better job of diagnosing people, or maybe there's something in the water. We don't know. But we're talking about *raising* a disabled child right now. We're with Stephen Gallup. He wrote the book *What About the Boy?* and his website is fatherspledge dot com. So you can read a lot there, as well as get the book. Now, Stephen, in raising your son, something people don't think about, but how does it affect your relationship with your spouse? That's got to be a tremendous amount of tension and difficulty.

**Steve:** That's certainly true. But like I said, when you have a *plan* that you can believe in, and you're partners in that plan, in our household—yes, there were up days and down days, but mostly we were a team. Other people who came over felt energized just being around us. So as long as we were going in that direction, I think all was well. But [*Sighs*] you mentioned studies, there've been studies about the prevalence of autism in particular, but there have been other studies showing that mothers are more prone to have feelings of—not good well-being or have more stress than the fathers do. We might not pick up on that at the time, just watching, but I think that was true in our family. My wife had a good deal of stress, and—you know, Mother's Day is coming up. We shouldn't need a special holiday to acknowledge people and show them some understanding, but if you know a mother who is anxious about her child, this would be a good time to show her some TLC.

**Evan:** What are some tips you can give people that are dealing with a child who has a lot of challenges, either for grandparents or for parents? What's some things that they could do?

**Steve:** Basically, emotional support is golden. Anything you can do that's constructive is probably going to be welcomed. For grandparents, my advice would be: Please do not suggest that you think this is anybody's fault. For example, if your son is the father of the child who has problems, please do not hint that, well you know, the mother's family is kind of strange, so—

**Evan:** [*Laughing*]

**Steve:** —Probably it's something from that side, or vice-versa. That kind of thing is not going to help anybody. The idea is to help both of them cope, and then to offer whatever additional assistance you think you can. Um, for *anybody*, please remember that the child is not the condition. Regardless of how you feel about the condition your child has, the child deserves and needs to be loved and related to in the same way any other child is.

**Evan:** Right. Right.

**Steve:** I already mentioned trying. Also, trust the doctor, but be prepared to think for yourself. If you don't think the doctor is taking your concern seriously, you may need to find another provider. Um, don't let your heart betray your mind. Just because somebody promises you something that sounds wonderful does not mean he can deliver on that promise. *I hope he can*, but if warning bells are going off very quietly in the back of your mind, you need to evaluate why. And finally, I'd say to be good to yourself. This is something we knew at the time we were going through this. We knew it on an intellectual level, but it didn't percolate down to an emotional level. But you don't want to—don't think you're supposed to

defer happiness until some future time when all this has been resolved. You need to be happy on a daily basis. You need to find a way to live in peace with the process.

**Evan:** Great, great advice. I've only got about another minute with this segment, but who's the best person who can get a lot out of this book?

**Steve:** Essentially, this is a *story*, it's about chasing an objective in the absence of dependable guideposts, which is something that I think a lot of people can relate to, including folks who've had other challenges, very different from mine. This book is not meant to be instructional. It's not a how-to or a guide for parents with disabled kids. It does map the terrain, and reading it may empower families to make better decisions, when they see how the decisions *we* made worked out for us. So basically, I would encourage anyone who'd enjoy a story about an uphill struggle to read it.

**Evan:** OK! Well, you can find the book at fatherspledge dot com. I'm sure—is it available at Amazon and bookstores, places like that?

**Steve:** Indeed. Amazon has it. If your local bookstore doesn't have it in stock, I'm sure they'd be glad to order it for you.

**Evan:** OK. It's called *What About the Boy? A Father's Pledge*. All right, Stephen, thanks so much for joining us.

**Steve:** Thank you, Evan, for having me on.

**Evan:** Take care. You know, we try to get as much information as possible for our listeners, because you don't know what people are dealing with. And it's great advice for people who, you know, are grandparents, in-laws, and your children are dealing with a disabled child. Don't play the blame game. That's a killer, right, Deb?

**Deb:** It doesn't work very well.

**Evan:** If you want to not be invited back for dinner, the blaming will do it. That will make it so you're not invited to Christmas or Thanksgiving. You've got to stay away from that stuff. That's one of the biggest pieces of advice I can give, because I've seen it in our own household. And something else that was said that was really interesting was, when you're dealing with your children, you've *got* to be on the same page. How often do you tell me that, Deb? You've got to agree. You've got to go in as a unified—group.