

Transcript

Better conversations. Better outcomes.

Episode 75 – Financial considerations for families with special needs

Bill Harmon - If you're a caregiver of someone with special needs that has an effect on your ability to save for retirement. So there are things that you should consider, things you should do in the planning process, so that being a caregiver and any of those time strains or financial strains does not get in the way of you retiring on time.

Jerry Hulick - If they're looking to take care of somebody and it may be an aging parent, or it may be a special needs child, but disabilities are now in all kinds of forms. People are working with disabilities more than they ever have, so the retirement piece and all the aspects of employment, and what benefits are through employment, have to be considered, in a holistic plan as to what's taking place.

Emily Larsen - Welcome to *Better conversations. Better outcomes.* presented by BMO Global Asset Management. I'm Emily Larson.

Ben Jones - And I'm Ben Jones, and on this show, we're going to explore the world of wealth advising from every angle, providing you with actionable ideas designed to improve outcomes for advisors and their clients.

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Emily Larsen - Under-served markets present the opportunity for a win/win situation, in which an advisor provides a valuable service to a community in need, and in turn, the community provides a new market and networking opportunities to the advisor. Today, two guests join us to discuss an important topic in an under-served community -- the financial planning considerations for families that include someone with special needs.

Ben Jones - At the top of the show, you heard both of our guests discussing why financial advisors should care about this topic. We'll let them introduce themselves.

Bill Harmon - I'm Bill Harmon, President of Corporate Markets for Voya Retirement. I am really proud of what we, as an industry do, in that we help Americans prepare for their retirement both financially and emotionally.

Jerry Hulick - My name is Jerry Hulick. I'm the principal and owner of Caring Consulting Group, which I've been doing now for the last 15 years. I do consulting work with businesses and corporations all around disability inclusion, and helping families that have children with special needs, and those with disabilities plan for their future.

Ben Jones - I sat down with Jerry and Bill at the Voya offices in Windsor, Connecticut. Voya has been an industry leader on this topic, and when I met with Bill and Jerry, they were both sporting different pairs of John's Crazy Socks, which is founded by John Lee Cronin, a young man with downs syndrome. If you're not familiar with them, we'll put a link in the show notes so that you can check them out.

Emily Larsen - One of the first things we wanted to understand was how they defined special needs. And to give us an overview of this community, here's Jerry.

Jerry Hulick - I generally break it down to four categories. The first is, what many of us think about when we talk about disability, is the notion of congenital disabilities, where they're born with this disability. You also have debilitating type disabilities where somebody may have a disease or something where they're going to get worse over time. You've got the overnight situation, the catastrophic event that could be a stroke or a car accident or something like that. Then these days you've got the aging population. We're so successful in our medical field we're keeping everybody alive, until they become disabled and then need care. That's one of the biggest emerging areas that we need to be dealing with, and all the financial backdrop that goes with each one of those disabilities.

Ben Jones - And so, for advisors that are interested in this topic, maybe you could start at the high level, like what is the size of the market, and how does this affect Americans in particular, maybe you have those stats.

Jerry Hulick - There's approximately 54M to 55M people identified. Now these are those that might have been in the U.S. census and self-identified that they had a disability, so if anything, it's understated. We see some disabilities like autism being looked at again, and the numbers keep coming down to now one of the most recent studies said 1 in 48 is being diagnosed. It's a huge group they've got as a group. I there's kind of a stereotype that this group doesn't have as much money. There's no cultural breakdown, there's no economic -- it affects everybody. And the disposable income is somewhere around \$650M of those with disabilities. And when we expand that to the caregivers that are also caring for these people, it's \$6.9T in disposable income. So these are people that also have the funds to do the planning to bring about the vision that they see for the lifestyle of the individuals involved.

Bill Harmon - Some of the stats I think that are easy to remember, Jerry had mentioned, one out of five Americans has or will have a special need or disability in their lifetime. One out of six U.S. workers is currently a caregiver of a loved one with special needs. So that sort of lays that foundation to say, if you're a financial advisor and you're speaking to a committee and you just listed those two stats, someone you're talking to on that committee is personally affected by what I just said. Caregivers spend, on average, over 24 hours per week providing care to their loved one with special needs. 30% spend over 40 hours per week. So you look at those stats and say, alright, it is time consuming. 9 out of 10 receive little to no financial support. Alright, so it's a big community, it's a lot of work, and they're not receiving financial support. So what then happens, and where -- we tie this into retirement, is that, on average, caregivers take out 40% more loans on hardships than the average. So it's affecting their ability to save. So I think obviously the next question is, well, what can we do about that? How can we -- number that preponderance to take out loans and hardships and keep them on the path to save for retirement.

Jerry Hulick - Because of the lack of understanding of disabilities, and some of the special programs and expertise that's required through government benefit programs and resource

tests and things like that, families require some specialty in their planning to include those with the special needs or disability, as well as the rest of the family's vision for their future.

Ben Jones - As we continued to discuss the topic, I realized how much larger this community is than I had originally understood. Jerry and Bill talked about the need to introduce dialogue around this topic as early as possible, even beginning with the very first fact finding meeting.

Jerry Hulick - If you're doing a complete work-up, fact finder, taking down information about a family, and you're not product focused, you're focused on solving what the needs of the family are, then you're going to be asking all the appropriate questions. Many times we don't get into, well, tell me more about your children. These families, particularly with the younger children, are not necessarily going to volunteer that there's a special needs situation if they don't think the advisor has any understanding of it. They've been, for lack of a better term, snake bitten by too many service providers over the years, and so they're very closed about the possibility, unless they think you understand. So I think it's first being complete in the questions that you're being asked and building trust. These relationships are built on a stronger level of trust to begin with. And that it's some specialized kinds of issues. You're going to have to spend a little bit of time understanding the specialty, per se. I mean, there's some specialized legal instruments that come into play. There's government benefits and resource tests that you can and cannot have. Those that are involved in long-term care sales have some concept that you can't add too many assets in your name for Medicaid qualifications. So some of those same kinds of things come into play when you're doing this kind of planning. So it requires a little bit of investment on their part. This is a grossly under-served group of people, and there's not enough financial practitioners that really understand this. And so, if I was looking for a way to expand my pie of possibility, so to speak, and I could add about 1/5 of the population that's been ignored, I would probably view this as investing a little bit of time to try to come up to speed. We've been ignoring these folks because we're a little afraid about it. We just don't know how to do that, so if we speak to it as if we want to help, we want to understand, and we do come up to speed in some areas, then this can be an incredibly great group of people to work with.

Bill Harmon - I think for many of the listeners, it could be foreign and a little bit overwhelming and intimidating, and I don't know how far to go before I'm over my skis. You know, there's a couple real basic things just to even start out with. I will share that I'm a caregiver, actually two-fold, in the sense that I've got a son with special needs and an aging parent as well, so we're taking care of two. If you think about basic questions, just to start out, everyone who's listening has probably worked with somebody on life insurance where you get to the point of designating the beneficiary. Just to even ask the question to say, do any of the people listed here have a special need. And the reason I ask, and then go a little bit into government benefits, and I'll share my own personal situation. It was Jerry that shared with me that if my son, who has downs syndrome, were to have over \$2,000 in assets to his name -- just \$2,000 -- and that could be because he's named as a beneficiary in mine, or his grandparents, or when something happened. That could actually make him ineligible for government benefits. Then what are you talking about with government benefits? Well, when I start taking my Social Security, assuming we did this right, he gets 50% of my Social Security proceeds on top of what I get. When I pass, he gets 75%. So suddenly he has this little built in pension plan, this little DB plan that most people aren't aware of. Or, he gets zero, because we did it wrong. We didn't have assets wrapped in a special needs trust. We didn't tell relatives don't name my son as a beneficiary. So there's very simple things just to start out with where if the audience of financial advisors, just when they're doing their daily routine of working with their customers just to say, I'd like to ask if any of these beneficiaries have special needs, you find as -- and you can get into some of the detail there, and just take these bite-sized pieces and feel more comfortable about, well, tell

me more about the government benefits. What should I know about that? Where can I get resources? And continue that dialogue until they're comfortable. If you say to your customer, there's a couple things I want to -- we've identified that you are a caregiver, did you know... And I would tell you, you'd probably know more than I would Jerry, that 9 out of 10 times, the response is no, I did not know that. And you just found a nice financial resource.

Jerry Hulick - And a client for life.

Ben Jones - You've added significant value to them.

Bill Harmon - And I think even the last thing too, for those that really engage in this, to get that type of response, you know. We've started out this conversation with it's a very under-served community. Being part of that community myself, it's a bit overwhelming. Even to the point of I've been in this industry for 30 years, and there were things that I didn't know about financial planning as a caregiver until I met Jerry, until I came to Voya. I think that is not just a client for life, but the reaction from your client to say you just found me money, I found a resource with you, I think that's really rewarding.

Emily Larsen - Being a resource for clients starts with being educated on the unique programs and opportunities that affect this community. In a little bit, we'll go over some of the specific programs you should be aware of. But first, we discussed some of the tools that advisors can utilize in order to become more knowledgeable on this topic. Here's Jerry again.

Jerry Hulick - There's two attorney groups that specialize in this area. Most of them came out of elder law, there's a Special Needs Alliance, and then the Academy of Special Needs Planners, which still says planners, but they're an attorney group. They both have websites and they have libraries with a lot of good articles that explain about different issues and case studies and things like that. I think a big aspect of what we're talking about here are government benefits. As much as Social Security is sometimes difficult to deal with, they've got an incredible website. There's a lot of information on there. You can literally, by source, talk about disabilities in regard to the various different sections, and become more and more familiar with that -- and just a general understanding. Going all the way, the American College, which does a lot of the credentialing for our industry, with CLU and CFP and all the others, they have a designation called Chartered Special Needs Consultant. It's one of their bona fide designations. It's a series of courses that you take, and it's going to get you into the legal aspects. It's going to get you into the government benefits, and a more broader understanding of disabilities and everything that goes into that. Then has kind of a capstone course, how to bring it all together in planning. That, right now, is probably one of the better places to go. Some of the law groups have continued education programs around the country, so if you kind of tie into some of those websites, or those organizations, the Stetson University has a CE program. They're the only university program I'm aware of out there that actually has a special needs law degree. And so you can go to their annual meetings, and they're incredible, to pick up currency as to what's going on and what's happening with legislation and all the problems, regulations under Social Security and things like that. It's like everything else. If I wanted to be a specialist in retirement plans, I've got to go bone up on the things related to retirement plans.

Ben Jones - Sure.

Jerry Hulick - If you want to be involved with estate planning, you're going to build some links to estate planning attorneys and understand the issues of estate planning. So this is just another

specialty area that I think is hugely rewarding, and yet probably the most neglected area in the financial services industry.

Ben Jones - Now, Voya's put together a lot of resources on this. Tell me a little bit about some of the resources you've put together to help advisors, whether they're working with plan sponsors or individuals.

Bill Harmon - Yeah, and I think it goes to that comfort level of taking the first step. And so, before you get into a lot of it complexity -- and I think that's really the biggest item. Is that, I don't want people to be overwhelmed by how complex it could be. We could get to that first step and then go onto a lot of the others. On our website, at Voya.com/voyacares, we have a lot of resources on even something as -- or a very good beginning item of here's a checklist of things you should consider when financial planning as a caregiver of someone with special needs. They're other resource items to understand integration with government benefits, just questions you should ask. So I think that's that beginning point of feeling comfortable to start the dialogue. From there, I would also add, as a planner, maybe find the right special needs attorneys, an attorney that specializes in special needs trusts, because a lot of that -- a lot of your conversations will end up going to should I have a special needs trust, what does that do, how much does that cost. I think you would also end up learning a lot too with the local -- and by the way, they could be your referral letter sources back and forth with the special needs attorney.

Ben Jones - Sure, that makes a lot of sense.

Jerry Hulick - A lot of local organizations, a lot of the non-profits have good websites themselves. There's some national organizations, like there's a National ABLE resource center, and that has all the information about these new ABLE accounts. You know, if you go to The Arc, if you go to the Easter Seals, they'll have sections. And when you find one that has a library, usually there will be case studies and stories. There are over 3,500 independent non-profits dealing with all the various different disabilities.

Ben Jones - Wow.

Jerry Hulick - There's one called NORD that is an association of the very, very rare disabilities, who come into that organization to have representation. It's a much bigger and huge community than we realize. When you think about the community itself, and all of the service providers that are doing things for them, all the various different therapeutic types of people all the way from aquatics therapy to the typical occupational therapy, and you start looking at that. So, once in this community, for an advisor too, that give you access to businesses and small businesses that are also serving the market. And you start looking at all these various different things and the services provided on the health side and everything else is pretty incredible as a market.

Ben Jones - Now we're going to get into some of the specific planning tools from entitlement benefits to special need trusts.

Jerry Hulick - You've got your entitlement benefits that we all pay for, right?

Ben Jones - Yeah.

Jerry Hulick - And their children's benefit that a child with disability will get comes under the entitlement side based on the parents' earning record.

Ben Jones - Okay.

Jerry Hulick - That's one of the most missed benefits out there, because people don't know about it.

Bill Harmon - So that's the one I just described.

Jerry Hulick - Exactly.

Bill Harmon - know you have an income that, once I take my Social Security, my son then gets that income.

Jerry Hulick - Or if he were to become disabled, his son would get an income. Or if he died prematurely, his son would get an income for the rest of his life. You've also got survivor benefits, which are many times missed, which when you have kids under the age of 18, and one of these life trigger events, then they're going to get benefits as well. So that's on the entitlement side. On the public assistance side, it's primarily Medicaid. On the entitlement side, it's Medicare, for all of us at 65. If you become disabled, you get Medicare then on the disability within two years. On the public assistance side, it's primarily Medicaid, which is more for the indigent, and those with disabilities. Then also SSI, Supplemental Security Income. Prior to age 18, the parents' income is looked at. After age 18, it's just the child, because they're their own person. So if their income is below the poverty level, basically, they can earn up to about \$1,170 in a month.

Bill Harmon - Of income --

Jerry Hulick - Of income.

Bill Harmon - -- or reimbursement of expenses?

Jerry Hulick - Of income. And then that's where they can't have more than \$2,000 of resource. So that's where the planning has to be around setting up certain accounts and things like that to make sure they're not in the titling. So that's Medicaid, SSI, and then you've got the food stamp program, maybe public assistance program for residential.

Ben Jones - And in the food stamps program, are there any special carve outs, or is it exactly the same application process for ...

Jerry Hulick - For everybody really, that's more ...

Ben Jones - That's what I was curious about. Yeah. What kind of grants and other things are available for folks from a planning perspective?

Jerry Hulick - You may have some of the non-profits that have grants, particularly for supports, like maybe equipment or assistant technologies, or scholarships for camps or things like that. Most of the people that we work with, if they can get something like that, then that's just all the better. But they can't plan around the maybe, so to speak, but they're out there. It's just building your sphere of influence and seeing where all these kind of things exist. Not too

dissimilar to sending a kid to college and you want to look at all the possible scholarships that might exist.

Bill Harmon - There's a lot of community boards too. I remember that in Colorado there are several community boards that then have funding for exactly what Jerry had said. It could be camps and the other types of therapy. It could be respite, actually, and that's one of the things we didn't talk about. That there's funding for respite for parents as well. A lot of organizations do that, which is really valuable.

Ben Jones - Yeah. A lot of our listeners will be familiar with the concept of a will or a trust. You mentioned earlier a special needs trust. Tell me a little bit about why these are really critical with respect to these situations.

Jerry Hulick - Well, a special needs trust, you can have first party, in which the individuals own money, like they got an inheritance. Or a third party trust, which is set up for their benefit by someone else. And there's language in the trust that preserves the eligibility for government benefits. So you can think typical kind of trust thinking, but this has special language that you can put money into with really no upper limitation as to the amounts and still qualify the individual for government assistance benefits.

Ben Jones - Now at least from my own personal life experience, these are really tight knit communities of families. So tell me a little bit about some of the ways that you think advisors can help enhance the client experience and connect people who might be dealing with similar situations or things that you've seen work.

Bill Harmon - And even give you another stat to tell you how big that is, and it is a very tight community, but only 56% of caregivers will tell their employer that they're a caregiver of someone with special needs. So it's kind of this --

Ben Jones - Wow.

Bill Harmon - Quiet group, but in a sense, I didn't introduce myself and say hi, my name's Bill and I'm a caregiver.

Ben Jones - Yeah.

Bill Harmon - If you then kind of broach the topic, they're wide open to talking about it and actually looking for the resource. Once that's the case, they're a very resourceful group because they've had to find all these things and navigate these waters on their own, and that network because of that resourcefulness is very tight. So I think the referral structure once you have one client, the referral process is incredible. From there, there's -- I'm thinking of everything I've been involved in, whether it be non-profits that I was on the board, camps that my son went to, different things where there's that community. In just all of those, we would have somebody come in and do a presentation on the different things in life, how to navigate an IEP at school, how to do financial planning for your children with special needs. That then opens up a huge network. Just within your community, to be known as the person that can do that, I think you'll have a line of people that are looking for resources. And it can go from can you just explain these items right here to me, what do I need to do, to financial planning, to I need help with a special needs trust, all of those items.

Jerry Hulick - Essentially on my team, as we're doing the planning, we started doing some workshops, I would meet different service providers that were doing different things. Sometimes particular to a disability or not. So rather than becoming an expert in everything, we would just host a workshop, I would do the introductions, and we'd introduce all these specialty people. Well at the same time my team's learning everything everybody is learning and you're getting exposure and you're building another resource network for yourself for referral purposes. It's a classic marketing 101. Just cultivating a market and using the resources that are there.

Bill Harmon - With very little competition.

Jerry Hulick - Very -- with no competition.

Ben Jones - And I think that's a really good point. Sometimes advisors don't like to dive into subjects because they're not an expert. But you don't actually have to be the expert; you can curate the experts and bring them together to help people solve real problems.

Emily Larsen - As in any field, continuing education is a must. Technology is leading changes in this community as in any other, and increased awareness is improving the futures for many in this space. Ben asked our guests about the innovations that are being made now that will shape the future of special needs planning.

Jerry Hulick - We've had full inclusion in the school systems now for over 25 years. But I think it's out more than it ever has been. I think there's less of a stigma around it. I think employers and businesses and corporations are starting to see the importance, and this group has capacity for employment that they haven't seen. So it's much more out. The opportunities and possibilities are there, there's more residential possibilities, more employment possibilities. So I think we're getting more and more comfortable that this is a part of our society and we have to stop ignoring it and deal with it.

Bill Harmon - I'd add there's some great technologies out right now. A client of ours has a whole area on taking an existing home and turning it into a smart home. If you are caregiving for a parent, from away, that they're in another state or so on, you can actually feel much more comfortable on monitoring their care from far away. There's another great organization that almost creates sort of concierge type of a program for aging adults that really helps find assisted living, doctors' appointments, things like that. There's a lot of advancement there. There's other organizations that are building communities of smart homes and integrating people with special needs with, even to the point we're talking about schools becoming more integrated, which really is a huge advancement for both those with special needs and everybody else.

Ben Jones - Yeah.

Bill Harmon - That awareness. I think the same thing within the workplace. There's been some really fascinating studies. In fact, one was just released by Accenture where companies that are embracing employment for people with special needs or disabilities have better financial results, better overall results. Fascinating new study. So I think all of this, we're really at this advent of taking it to that next level.

Ben Jones - I want to just ask some closing questions. Maybe I'll start with you, Jerry. What does it feel like when an advisor helps get this planning right?

Jerry Hulick – Like I said, I get more excited remediation in this group. I mean it's because you immediately see it. I've had many families say to me particularly, I just want to live one day longer than my child. That's the worry, is what is it going to be like when I can't control things anymore? So as they are able to check things off saying, I see that that's taken care of; I can feel good about that now, the anxiety level that comes down. We're never going to get full peace of mind until we can predict the future. But that's what you see, that's what you feel. I've had people get up and come across the table and give me a hug at the end of a plan. I didn't used to get that.

Ben Jones - So what does it feel like, Bill, I mean you've been out in the marketplace, you've seen a lot of employers embrace different approaches. What does it feel like to be on the receiving end, like a client that receives this great advice from an advisor?

Bill Harmon - It's a couple -- we've had very similar responses where we'd be doing a presentation on Voya Cares and suddenly we notice that there are a couple people crying. I think it's because we touched on something that just no one talks about. That was very refreshing. Even to the point of plan sponsors or advisors, or actually quite frankly, coworkers. People that when we're looking at being that employer of choice in a very competitive employment market, it attracts top talent. Just that very basic, if I am this person that went to school or went straight to work and I started to save money, and I met someone special and we decided to have a family and poof, I retired. How easy is that? And I planned accordingly. Life doesn't happen like that.

Ben Jones - Yeah.

Bill Harmon - Life happens where you have these deviations off that financial planning path. I think there's such a relief for our audience, our clients to say, someone gets what my life is about and talks to me in that manner. Personally, I find it's fulfilling as I've never liked different flavors of vanilla and this feels very different and fulfilling.

Ben Jones - Wonderful. Jerry, if you were to summarize our entire conversation today in one or two sentences, what would you say?

Jerry Hulick - Just recognize this is a huge consumer group that needs help, wants help, and will appreciate your help.

Ben Jones - Bill, last question. So for the folks listening to the show that want to learn about Voya's work in this area and follow your work on the subject, how can they learn more?

Bill Harmon - For one, they can go to Voya.com/voyacares. You'll learn about Voya Cares and what we do for the special needs community and their caregivers. I'd also encourage them to reach out to their local representative who can then provide a little bit more color. Again, I think that they would really appreciate the uniqueness of our approach here.

Ben Jones - Wonderful. Well I really appreciate you guys making the time here to discuss this topic with us. I really appreciate it.

Jerry Hulick - Our pleasure.

Bill Harmon - Thank you very much.

Emily Larsen - We identified many specific resources in today's episode. Rather than listing all of them, you can visit our show notes page at bmogam.com/betterconversations to access links to all of them.

Ben Jones - I was totally impressed with the way that Voya has championed this topic throughout the industry from their senior leaders, among their associates, and with their clients. Jerry, Bill, thanks for making time to share your passion, expertise, and experiences on the topic.

Ben Jones - Thank you for listening to *Better Conversations. Better Outcomes*. This podcast is presented by BMO Global Asset Management. To access the resources discussed in today's show, please visit us at www.bmogam.com/betterconversations.

Emily Larsen - We love feedback, and would love to hear what you thought about today's episode. You can send an e-mail to betterconversations@bmo.com.

Ben Jones - And we really respond.

Emily Larsen - We do.

Ben Jones - If you thought of someone during today's episode, we would be flattered if you'd take a moment and share this podcast with them. You can listen and subscribe to our show on Apple Podcasts, or whatever your favorite podcast provider is. And, of course, we would very greatly appreciate if you'd take a moment to rate or review us on that app. This show and resources are supported by a very talented team of dedicated professionals at BMO, including Pat Bordak, Gayle Gipson, Matt Perry, Derek Devereaux. The show is edited and produced by Jonah Geil-Neufeld and Annie Fassler of Puddle Creative. And these are the real people that make this show happen, so thank you. Until next time, I'm Ben Jones.

Emily Larsen - And I'm Emily Larson. From all of us at BMO Global Asset Management hoping you have a productive and wonderful week.

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