Donald Schumacher Oral History.
Biography

Dr. Donald Schumacher, now retired, has served as the President and CEO of the National Hospice and Palliative Care Organization (NHPCO), the National Hospice Foundation, the Global Partners in Care, and the Hospice Action Network. In his four decades of service to children’s palliative and hospice care, Dr. Schumacher advocated for federal policy protections for concurrent care for seriously ill kids, opened numerous hospice and palliative care services that accept and treat kids, and was a global leader in children’s advocacy for hospice and palliative care.

Interview Abstract

Dr. Schumacher begins the interview describing how his career plans changed after hearing “a very unbelievably moving lecture” from Elisabeth Kübler-Ross in 1975. Dr. Schumacher subsequently began his clinical work in both the adult and pediatric end of life care. Dr. Schumacher then recalls that as he became more focused on pediatric hospice care, he was met with a lot of clinician resistance such as “We’re not interested in pediatrics. It’s just too difficult, it’s too painful.”

Dr. Schumacher then describes transformative moments of his career such as his reflection on giving a lecture at a pediatrics conference in New York when the 2001 World Trade Center bombings occurred. He also reflects that clinician resistance to children’s palliative medicine was similar to the clinician resistance toward treating patients for the HIV/AIDS during the 1980s and ‘90s. After these reflective moments, Dr. Schumacher’s takes discusses his role organizational management and lobbying for federal legislation. Throughout his career, Dr. Schumacher successfully advocated for children’s concurrent palliative and hospice care with aggressive curative treatments to be included in the federal Affordable Care Act.

Dr. Schumacher describes initial clinician resistance to children’s palliative and hospice care to be one of his largest barriers in his career. He also describes his frustration with some clinicians who refused to innovate with new best practices. Dr. Schumacher concludes the interview with his dream for the new cohort of children’s palliative advocates to continue working towards integrated pediatric palliative and hospice services that provide streamlined and seamless service to patients and their families.
## Glossary of Acronyms

<table>
<thead>
<tr>
<th>Abbreviation</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>AIDS</td>
<td>Acquired immunodeficiency syndrome</td>
</tr>
<tr>
<td>CMS</td>
<td>Centers for Medicare &amp; Medicaid Services</td>
</tr>
<tr>
<td>CNA</td>
<td>Certified nursing assistant</td>
</tr>
<tr>
<td>HIV</td>
<td>Human immunodeficiency virus</td>
</tr>
<tr>
<td>NHPCO</td>
<td>National Hospice and Palliative Care Organization</td>
</tr>
</tbody>
</table>
Interview Roadmap

Beginnings

Personal career influences .................................................................1-2, 5
Colleagues, mentors, mentees, and other influential figures ..................1-3, 5, 9, 14

Pediatric hospice care

Evolution and history of pediatric palliative care ..................................1, 4, 7-8
Legislative policy and lobbying...............................................................2, 4, 6-9, 12
HIV/AIDS epidemic..................................................................................3, 15
Children's suffering and awareness of death and dying.........................4
Research ................................................................................................1-4
Challenges ...............................................................................................3, 6-7, 10-11, 13
Successes ...............................................................................................8, 12, 14-15
The future .............................................................................................11-12, 13-16

Adult hospice and Pediatric palliative and hospice care

Clinician resistance ................................................................................3, 6-7, 10-11
Adult movement paving the way ..........................................................9
<table>
<thead>
<tr>
<th>Mention</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>Armstrong-Dailey, Ann</td>
<td>2, 5</td>
</tr>
<tr>
<td>Franz, Tom</td>
<td>2</td>
</tr>
<tr>
<td>Grollman, Rabbi Earl</td>
<td>2</td>
</tr>
<tr>
<td>Kübler-Ross, Elisabeth</td>
<td>1, 2, 9, 14</td>
</tr>
<tr>
<td>Saunders, Dame Cicely</td>
<td>9, 14</td>
</tr>
<tr>
<td>Weisman, Avery</td>
<td>2</td>
</tr>
</tbody>
</table>
Today is July 12, 2019. I am Bryan Sisk. I am in St. Louis, Missouri interviewing Dr. Donald Schumacher on the telephone for the Pediatric Palliative Care Oral History Project. Dr. Schumacher is in Edgar Town, Massachusetts. Well thank you Dr. Schumacher for joining me today. To get us started could you just tell when your mind turned toward palliative and hospice care as a career focus?

Donald Schumacher: When I was a young man, I had a couple of deaths in my family which were largely unresolved as I was going through my youth in teenage years and into early college years. In my college years I had the opportunity to hear Elisabeth Kübler-Ross—in fact she did a lecture at the school that I was at. The lecture was on The Dying Child. It was a very unbelievably moving lecture and also really changed my entire future. I had planned on getting my masters and doctorate in clinical psychology and opening a clinical practice, but after I heard her speak, given my own unfinished business in my own life, end of life care, pediatrics, hospice, adults, children, everyone, it all crystallised in that lecture. I decided that was what my career was going to be. So I finished all of my masters and doctoral work by doing internships and work around end of life care related issues. Then I started a hospice program in Massachusetts, ran one in Buffalo, New York, and took on the National Hospice Organization for 15 years. Really it's an opportunity for me to try and make sure that the things we've all learned over the last 10 to 15 years continued to be increased by everyone and appreciated for kids and their families. So, it began with a personal quest probably, and then became a personal and a professional one when I heard her speak.

Bryan Sisk: So what was it about her talk that grabbed you?

Donald Schumacher: The big issue or the big thing is that children know they are dying and whether they can articulate it or how the articulate it is very unique and different and changes from child to child. Her whole focus was on encouraging people in the audience to pay attention to their own fears, sadness, and anxiety—not to let our own individual fears and anxieties blind us to what children maybe asking us for or trying to talk to us about. It was so incredible and moving, and she had a million and one stories and references because she had done a lot of work with kids at that time.

Bryan Sisk: So was the care of these children, was that central to your career in the beginning? Or was that something that was as part of the broader portfolio of what hospice and palliative medicine became?
Donald Schumacher: I sort of went right to it. Got very involved with a lot of pediatric and end of life care conversations that were taking place. I felt at the time that I wanted to have as broad a range as possible, so I was doing a lot of adult work as well. I sort of knew as a part of my training and my future that I would be doing something that would eventually improve access for kids to good care at the end of life, and that the hospice and palliative care would not be a forced choice for their parents. We can talk about that in a little bit, but we were very successful in getting legislation passed to allow hospice to be offered simultaneously with aggressive therapy which was a lot of work but was well worth it every minute of it.

Bryan Sisk: So when you were starting out, I assume that talk was probably was like in the mid-70s then?

Donald Schumacher: 1975 exactly.

Bryan Sisk: So did you find a lot of similar minds, other people that were interested in the suffering and dying of kids?

Donald Schumacher: There were a growing number of people who were interested in children's work as well as adult work. I was trying to bounce back and forth between both fields, but at the time I was doing this, I was doing a field placement at Roswell Park Memorial Institute. One of the guys that I was very good friends with and another doctoral student, he was working in the pediatric unit. We did a lot of conversation back and forth about work with pediatrics and similarities in adults and differences from adults. Along the way, I ended up initially putting more of my time into adult treatment. But my work with him—and then with a whole slew of other people who were getting very, very interested in pediatric care, really moved me into a very different direction of my original plan, which was to do therapy. A lot my earlier clinical work was focusing on dying kids and their families and the impact of a dying child on, certainly the child, but then their family. The longitudinal struggles in the family and the parents with dealing with the loss of a child at very young age.

Bryan Sisk: So who did you really learn from the most early on?

Donald Schumacher: Kübler-Ross, Avery Weisman at Mass General, Rabbi Earl Grollman, a rabbi in Belmont, Massachusetts, did a lot of work with children. I would focus some of my graduate work on pediatrics, so there were a couple of instructors, Dr. Tom Franz of the University of Buffalo, was very, very helpful in that. I got very involved with National Hospice and Palliative Care Organization which had a whole series of opportunities, one of which was working with children. I became—not a staff person, a board member that
participated in that committee and did a lot of work trying to advance the conversation with kids and as well as with adults. Ann Armstrong-Dailey at Children's Hospice International—I was very friendly with Ann for a number of years. We didn't go very far in our relationship because of the way she was choosing to manage her business, but she did do a lot of good things in raising the awareness of pediatric care and kids. So it was a tough relationship in some ways, but I did learn a great deal from her.

As you were talking about kind of bouncing around from pediatric palliative care to adult palliative care in different hospices, what were the views in each of those fields of the other field? Were they viewing each as part of the same thing or were adults viewing kids as part of a hospice movement? Was there an appreciation of a need for pediatric specialist? What was kind of that developing milieu at that time?

Donald Schumacher: That's such a great question, it took a very long time for pediatric and end of life care to really become integrated into most of the hospice are in this country. Part of the reason is, and you would know this better than anyone, nurses, social workers, physicians—they make a decision early on if they're going to work with kids or adults, and a lot of the doctors and nurses that were working with them in the early years said very directly, "I don't want to do pediatrics. We're not interested in pediatrics. It's just too difficult, it's too painful, the conversation would be too awkward." Really put up, not barriers, but resistance I think at the very beginning. I remember one nurse I was working with, “But I worked for a thousand years to become an adult practice nurse. Kids are too difficult for me to deal with.” So, it took us a long time to continue the conversation between was happening with adults and with kids. At NHPCO [National Hospice and Palliative Care Organization] every year we would put on a national conference, but every two or three years when I was president, we focused our conference on pediatric care. I was working, really pushing people to really open their doors and find ways to admit access to these kids into their programs and not to be afraid of working with them. It really was a labor of love and it ended up actually great, because pretty much every hospice in the U.S. now takes pediatric cases that are coming in.

How was your reception?

Donald Schumacher: Well, there was a lot of resistance at the very beginning. "Hospice was for adults," I kept hearing over and over and over again. I kept on saying hospice was for everybody, anybody who needs the care at the end of life. It took a lot of patients and pushing the issues and really beginning to advertise some of the work that pediatricians, the researchers, the nurses, and the hospices that were doing kids then. Quite frankly, very honestly it was a very similar
dynamic to becoming very active in the AIDS [Acquired immunodeficiency syndrome] movement as well in the early 1980s. A lot of people with HIV [Human immunodeficiency virus]/AIDS were not interested in hospice or palliative, or end of life care because, again all young guys, mostly; wanted to keep on going; did not want to die. Very difficult, very painful. And a lot of the hospices resisted like crazy taking care of the HIV cases. Now of course, the issues are very different, the resistance was similar and that was something people are relatively unfamiliar with and they were afraid to take the leap in jumping to these programs. They didn't know how to deal with them and it took a lot of training and education which it was really a lot work, but eventually it was wonderful.

What do you think was the biggest challenge for kids that were really dying at that time back in the 70s? Was it lack of access to hospice or was it something else? What was the big challenge for them?

The big challenge—when I was 19, which would have been 1969, my best friend died of leukemia. His parents made the decision, as pretty much everybody did back then, not to tell him that he was dying. I could see by the look on his face the last time that I went to see him, that he knew that something serious was going on, but the look was like, "Please, somebody tell me the truth in all of this." The biggest obstacle was the resistance on the part of the medical nursing community and the parents to accept the notion or the concept that talking about this was better than not talking about it, and finding ways to work with kids who were interested in having the conversation really became the focus to what we were doing.

Take me through a little bit of your early history. I see you developed this interest in hospice and palliative care. When I look at your CV, all of sudden, you're running hospices and running organizations, so what happened those two things? How did you do that?

I began to realize that one of my strengths was the ability to organize and lead an organization. I felt that I would be more successful, rather than doing individual treatment or working with kids, that I would better off taking up policy perceptive and trying to push the conversation legislatively and financially. So, I decided probably about in 1984 or '85 that I wanted to go from direct clinical work with kids and with adults and really put my energy to policy to developing the appropriate services to be necessary to take care of these populations. At the heart of every decision that I made, and that we all make around legislation and or policy, is the benefit of the individual patient or family; the child or the HIV patient. I decided that I really wanted to do something on a policy level, rather than only working with individuals, but I did keep a private practice the entire time I was working in hospice.
Interviewer: Bryan Sisk  
July 12, 2019  
Interviewee: Donald Schumacher  
Page 9 of 21

Probably, when I went to Washington, I began to cut that back because I couldn't do both, and both interests at the same time.

[00:12:28]

Bryan Sisk: So then what were your personal challenges—your biggest challenges as you were trying to develop this career and push this field forward?

Donald Schumacher: The frustration with medicine, who resisted very, very strongly the opportunity to discuss the issues either with the patient or with the family. So there was a lot of resistance, a lot criticism, a lot of people coming down certainly on me, but on the hospice movement. Some people thought it was very inappropriate for dealing with kids. What actually changed that was that I began to develop strong relationships with people who have lost children. They wanted to do some work to try and advance the conversation and have a child talk about hospice and palliative care much sooner in the disease trajectory. It was really parents and kids, and the needs of parents and kids that acted as a way to keep many of us going in the field. But my frustration was the resistance to try to look at things differently. It was always the case of "you don't talk about death until it's over." I was the exact opposite "You talk about death before it gets closed." I think ultimately that's where we are now.

[00:14:04]

Bryan Sisk: You had talked about through your work, hospices in New York broadly were accepting children by the time you finished that. How long did that process take?

Donald Schumacher: Well, interesting you asked that part of the question. On September 11, 2001 I was walking onto the stage of the pediatric conference in New York State on end of life care with children—for them, when the first plane hit the tower. That was just such an unbelievably difficult, of course, day and experience for years to come. I've often stopped and looking back at it, isn't it interesting we were doing pediatrics the day that the towers were hit? I got involved a little bit more with different folks who were doing the pediatric thing. Ann Dailey as I've mentioned. She was working with me up in Buffalo at the time, and she at that conference as well. The first thing that I did was I said to everybody in the room, "We're shutting the conference down," because we were in Albany and many of the people there were from New York and they were all of course, having such a hard time, it was very difficult. But I ran out in a car and drove everybody from Buffalo in our program back to Buffalo. The irony—not irony, but the immense feeling—I've got this car of pediatric folks who had wanted to look at pediatrics and children, and we are driving back to Buffalo to avoid—to get away from what we've just experienced around the towers. It just overwhelmed me with this energy of how in the midst of what you're dealing with in your life sometimes unbelievable things forces you in a different direction. From that point
forward I was really more and more committed to pediatric care. I got involved with a variety of different groups, it was so meaningful and so important to deal with.

Bryan Sisk: So what about outside of New York, do you have a sense of nationally what was the openness of hospices that were taking these kids in?

Donald Schumacher: I would imagine that by the time, probably at the end of 80s into the early 90s they would increase that. There were more and more hospices looking at it, the opportunity to serve kids. Then into the 2000s, national organization, I took over the leadership of that in 2002, and it became a major focus of my life, my professional life. I was determined to get a different piece of legislation, so that when parents are having these conversations, they don't have to give up aggressive therapy, but at the same time they're talking about hospice and or palliative care. And we were able to get that legislation in the Affordable Care Act, it took a while, but we were able to get it in there. And now, it's not perfect, but it's better than it was. If I was still working, I really would be doing a lot of focus on increasing access to quality care at the end of life for kids, either hospice or palliative care, that would still be a major focus for me.

Bryan Sisk: We mentioned it a couple of times, could you talk a little bit about what that journey was to try to make legislative changes?

Donald Schumacher: Legislation, they talk about it being sausage-making and it's really true, you never end up where you want to go, and you always end up in a place that's very different where you started. We had a lot of resistance. I had to deal with the pediatricians who were upset with us, they didn't want necessarily it to be—they were resisting hospice because they didn't want to talk to family of kids that were dying. But when we talked about legislative change, for a while there they were very freaked out. So I had put together a whole group of pediatric docs who were interested in this process, met with them quite a bit and did some work with the Academy of Hospice and Palliative Medicine, The Hospice and Clinical Nurses Association, really began to try and structure more and more interest. I was able to find in the Congress, quite a few staffers—not necessarily congressmen, although many of them came around by the end—a lot of the staffers who had experience with end of life care of kids. And we really built a grounds for us for when we were working on—or when Obama was doing the Affordable Care Act, we were able to insert this into the legislation. We really had done our homework, with a lot of long conversation and hours. But that's what ended up doing it, was putting together the appropriate people, with some of the experiences. The good thing about hospice and palliative care is people really have an awful experience, or they had a great experience. If they've had a horrible
experience, they want to change it, if they've had a great experience, they want to promote it, so we were trying to do the same thing with kids.

[B00:19:03]  
**Bryan Sisk:** Was this something that was kind of a hurry-up and wait? You heard that they were developing this health care bill and then get everything together and then wait for the right time? What was the process and what was the timeline of that lobbying you were talking about?

**Donald Schumacher:** We were started at the very beginning of Obama's presidency and when it became clear that he was going to do health care reform, which would have been—I guess it would have been maybe '11, '12, '13. We just got very aggressive. In addition to what I was doing, and the staff at NHPCO, we had a very strong series of lobbyists who were very interested in pediatric care. Probably you're exactly right, I mean Washington is "hurry-up and wait", but we were hurry-up and wait and we saw progress and that they just didn't count it out of the gate. It really became very, very popular eventually with pediatricians and we were forcing people to talk about it. We just gave people the choice that you don't have to give up aggressive therapy in order to keep the conversations going.

[B00:20:21]  
**Bryan Sisk:** You mentioned that when you start with legislation you never end up where you wanted and you never end up where you started. What were the big things that you had to give up to be able to get a concurrent care within 6 months in the end of life?

**Donald Schumacher:** We wanted them to make it a part of healthcare requirements of all healthcare systems, not just with Medicaid. So we were able to get in the legislation in Medicaid, but then after that I had to do a lot of work—and we did we did. We were actually quite successful at getting most of the third party payers to follow along with what Medicaid was doing. So right now any Blue Cross program in the United States, you could have hospice and aggressive therapy simultaneously with kids. Still with adults, it is still you have to at some point in time deselect aggressive therapy and relax, if you will, into palliative care, but you don't have to do that with kids. It took us some time to get that moving with the commercials, but we were able to do it. There's a couple of pivotal physicians who are very helpful in working on that with me.

[B00:21:35]  
**Bryan Sisk:** I want to take a step back a little bit and think about pediatric palliative care as it developed. When you were starting out, there was no pediatric palliative care field. Hospice eventually kind of melded into this philosophy. When did you first hear about or think of pediatric palliative care as its own—not only discipline, but its own mentality outside of it, specifically at hospice?
Donald Schumacher: I can't track down when that actually would have been. Several things were going on at the same time. I think it was before we got the legislation but there was a—the national organization when I took over in 2002, I developed a sub-committee of the board that was focusing on palliative and hospice care for kids. That would have been 2003 and '04. We were really determined, I was really determined that it would remain a focus of what the board activity was. I integrated it into pretty much everything that we were doing in the organization. We were working with adults in nursing homes, we are working with CNAs [Certified nursing assistant], and we were working with pediatrics. These are specially groups that I felt needed to have their own focus in the organization. That's probably in the 04s and 05s is when it got really pretty aggressive.

[00:23:11] Bryan Sisk: What do you think was the big spark that really started the movement of palliative care for kids?

Donald Schumacher: I don't think there was one spark., I think there were pivotal people who were interested in doing pediatric care and began to do quite a bit of writing and speaking about it. I think when that began to get more popular, the conversation about working with kids became more popular, then I think it really began to take off. One of the things I know was important was we did workshops—we developed a training program at NHPCO on how to take care of kids that were dying and why this was different than working with kids who were dealing with an illness from which they potentially would recover. So by setting it up at the very beginning, not just things to have conversation about, but also how you can learn to do it, we got a lot more people interested in it. I can tell you—what year was that; it was probably in '04 or '05. The focus of our clinical meeting one of those years was only on pediatrics, and we had a huge number of people come. It was great, a great turnout, because we were recognizing there needed to be something different done. They wanted to have the education and training part of it, not just, "Gee this might be a really good idea," but the real issue of "how do I make this a really good idea?"

[00:24:44] Bryan Sisk: So within NHPCO, when you developed this sub-committee for palliative care for kids, what did it lead to? After you started that, what were the outcomes, successes, and spin-offs that you saw?

Donald Schumacher: We did a very comprehensive training manual which was one thing. Then there was the conversation "Gee, will parents ever except palliative or hospice care for their child while their child was in fact dying, but they couldn't accept it because they didn't want to deal with it." And that begin the conversation about the legislation that was probably in '08, '09, and '10. The educational offerings were beginning to, I think, generate a whole lot
more interest on the part of the hospice and palliative care community. It has some pretty significant speakers that were interested in advancing this as well. Then we did another conference, the clinical conference that focused on pediatrics, a year or two later. We just kept on hammering them over the head with the fact that conversations are important, developing education in order to make it happen in your hospice program, and oh yes, let's look at what legislation is going to take. The legislation took a little bit of time to get it moving, but once we were able to on the Hill and having the conversation, really we began to see really positive turnouts for a while. It was all not dependent on pediatric care, it was all going to be dependent on whether or not there was going to be any change in our healthcare system. But even though they cut it back and all of that, this part of the Affordable Care Act remains in place which I'm very proud of that.

Bryan Sisk: So one thing that strikes me in thinking about legislation and politicians is that often they need to be moved by their constituents as well, which means you have to move their constituents. But talking about dying children is not something that's palatable to a lot of people in the public, so how did your organization balance that?

Donald Schumacher: Every year we had a policy day on the Hill, our management meeting, which always took place in Washington D.C. When I took the job over I made sure until I left, we kept the management conference in Washington because people needed to be able to go on the Hill and to lobby. So when we had our focus on pediatric education teaching training, we would have our policy day focus on pediatric care. What we would do is we had doctors, nurses, patients, families with kids, we had anybody that had any kind of experience with serious and or life threatening illnesses, come to the Hill—sometimes we had upwards to 500 or 600 people. And they would go office to office and do the lobbying. Some of the congressmen and senators were quite impressed by all of this, because usually when you're trying to pass legislation you've got the CEO of your organization coming in, but we made a decision to bring in patients, family members, and kids. That made the big difference, it was a huge hit. So we began to talk about the changes in legislation, we had a bit of a track record in talking with the various offices. Those office to office conversations were really, they were really wonderful

Bryan Sisk: So, thinking more broadly again about the adult hospice movement. Thinking of it starting with Cicely Saunders and Kübler-Ross, and eventually starting this movement in the United States, how much did that movement affect the development of pediatric palliative care?

Donald Schumacher: It was absolutely huge. At the very beginning everything started with adults and people who are afraid to ask the question "can we do this with children,"
because it would still a loaded, very loaded idea to have a conversation with
the family and or including or not including a child about the fact that there
was a terminal illness they were dealing with. The overall increasing of the
movement was a huge piece of—what's the word that I want—canvas we
could paint the pediatric piece on. It became successful in that it was the next
phase of something that we had—you probably notice about hospice and
palliative care—a lot of the people that got in this field, especially back in
the 70s, 80s, and 90s, we were determined to change the system. We were
determined to change things there were not going the way that we thought.
In pediatrics at the time that that happened, it was the next phase that needed
to change in end-of-life care. That was one of the most exciting parts for
those of us who were working on it.

[00:29:54]
Bryan Sisk:
Do you think that pediatric palliative and hospice care has remained a part
of this larger hospice movement or did it spark from that and then they've
been developing in parallel?

Donald Schumacher: A little bit of each. It's interesting it's not just the pediatrics, but there are
numbers of physicians in the field these days, who I feel personally who have
regressed a little bit and that they don't want to talk about palliative care as
an example as having something to do end of life care and or death and or
hospice. There are some physicians who we struggle with who are essentially
wanting to change the description of what palliative care was or how you
talked about palliative care. Now the truth is, is all hospice care is palliative
care, but not palliative care is hospice. Absolutely the case. So for kids and
for adults both, you need palliative care as you go through the trajectory of
your illness, not only towards the last 20 minutes of a person's life or a child's
life. But people were getting afraid that people were not going to be able
good end of life care if was death still attached to palliative or pediatric care.
So it was quite the struggle. I think that calm down a bit after the legislation
passed. But there's still quite a bit of conversation out there that we don't
want to have too much pediatric care associated with hospice—not so much
with palliative care, but with hospice. Our work was cut out for us and it still
is cut out for us. I don't know how successful things are going these days,
but I don't think you can eliminate the opportunity to discuss dying along
with the fact that we're discussing pain and symptom problems with an adult
or with a child. It's an ongoing conversation. I think what you're doing now
will be helpful in the field for raising the awareness of why this is important.

[00:32:05]
Bryan Sisk:
That resistance, was that coming from people who primarily care for kids,
primarily cared for adults, that primarily worked in hospice, worked
primarily in more of a palliative care position, or was it from all sides?

Donald Schumacher: It was more in a palliative care position mentality.
Bryan Sisk: That's interesting because what a couple of other people have mentioned to me is, this kind of on-going debate in pediatric palliative care, especially about what palliative care means and it's no longer end of life purely like you were saying, but then how do you even interpret terms like "life limiting." Does that mean they're going to have a shorter life or they're going to have a long life where they can do less and they're going to have chronic illness. From your perspective, how have you seen that development overtime?

Donald Schumacher: What I think that's it's increased in some spheres because these are very hard conversations to have absolutely; not even necessarily talking with the child, but talking with the family. These are very, very difficult conversations and no one ever said that they were ever easy, but I don't think it's appropriate for us to roll back years to having the fact that you can't talk about death again. And that's what some people were encouraging to do. I thought that quite a bit in the last couple of months when I was in my job.

Bryan Sisk: Another question that I think you will be uniquely suited to help me explore; I've heard about different tensions that are starting to arise in certain areas between community-based hospices and then palliative care teams that are hospital-based, and some of them have reached out in the community with their own—so how is that developed?

Donald Schumacher: It's been a challenge. When I was running a hospice program up in Buffalo in 1995, we had added palliative care to our name, we were the Center for Hospice and Palliative Care, because I felt very strongly that palliative care was the natural entry point into a good comprehensive end-of-life hospice experience for the individual person. As time has gone on, and education and training has become more available around the areas of palliative care, you're exactly right, in hospitals there is that development of a great number of palliative care teams. They struggle however, when you refer that patient out of the hospital, you refer that patient to hospice, you refer to a skilled nursing situation, I mean where do you refer that patient to? And I, again, was fighting this. After all we've done for the last 30 or 40 years, I don't think it's appropriate for any person to say "you can't talk about dying" in the context of palliative care. You don't have to talk about it, but it shouldn't be something to be avoided. I think that there's a major control issue that was taking place. Hospices last year, I think, took care of, I'm not sure how many millions—maybe like 1.8 million people, something like that. And we don't know how many palliative care folks were taken care of because there really isn't the same kind of a system keeping track of it. The hospices kept track of it by the reimbursement that we've seen and palliative care is going to be always different on the reimbursement—it's going to be much more a philosophy to the payment stream. So there's lots of reasons why this is
complicated, but I do think it became very troubling for some people to have to face the fact that if they really want this to be continuing, they're going to have to have some relationship with hospice, especially if the patient is discharged from the hospital. They may have palliative care teams in the community to take care of them, but there is no reimbursement for that yet, and I think that's something that it's going to be a problem.

Bryan Sisk: So what do you think is the big barrier that makes it hard for that hospital-based team work closely with the community-based team?

Donald Schumacher: The death—the conversation about dying. I think that's still a big part of what the problem is. I've been up on a soapbox whenever I've had the opportunity to say "this is not something that can be turned back or ignored." Believe it or not, we are all going to die. You don't have to talk about it and you don't have to talk about it a way that's unfamiliar to the patient or to the family, but you've got to be open to that conversation, it has to be something that's at least possible.

Bryan Sisk: So another thing I'm interested in is talking a little bit about regulations and how that has impacted, in both good and bad ways, the care that hospices are able to provide, especially for their kids. I'm thinking of—I think it was yesterday or the day before, there was some federal report that came out and was talking about all of these different lapses, or problems, or citations of hospices and the question that came to mind was, were those examples of poor care? Or were those examples of people at the end of life that wanted to do things that would not be deemed safe on a checklist or on a mixer? So how have you seen regulations for hospice change overtime, and has that been things that have been for the better, for the worse, or a mix?

Donald Schumacher: Most of the regulations, they remain relatively stable. The CMS [Centers for Medicare & Medicaid Services] right now is noodling around with the claims, not necessarily any of the services or the quality of the services provided. But what you've just identified is one of the other things that I've working on before I retired, and that was many of the hospices in this country was not being surveyed by Medicare. You can be a hospice provider and not be a surveyed in some states for 20 years, believe it or not. 20 years! So we got legislation passed just before I left that now requires that every hospice is surveyed at minimum of every three years. And they're finding now these discrepancies or these deficiencies if you will, because these are programs that have not been surveyed in many, many years and they're finally being surveyed. So, I say "Hurrah! Hurray! This is exactly what I wanted to have happen." Hospices have got to be accountable, and they were getting away, not that they were trying to get away, but if nobody is looking at what it is you're doing, you can get away with a lot of stuff. It's a little bit troubling for
the hospices now, it's a great opportunity for them to be recognizing how they can clean up their act and eliminate the these deficiencies. There was always deficiencies that you got under hospice, and under healthcare just generally—hospitals, nursing homes, home health agencies, everybody. But hospices were so infrequently surveyed that I always thought the potential for greater problems were there, and now I think that we're seeing that is the case and it's going to be greatly eliminated as time goes forward. It's a really positive thing.

So looking at the legislative accomplishments that your group has been able to lobby for, what do you think are the biggest legislative changes that are still needed right now?

Donald Schumacher: The 6 month or less criteria does need to change and I've been saying that forever. They did that at the last minute when they were doing the legislation in 1984 because they thought it was too generous to balance it if you didn't have a time limit on it. I think there needs to be something that changes the time limit. I wouldn't—I would try and get away from time-based review or reimbursement, but I might look at it acuity-based reimbursement or something with another way to approach the illness—not necessarily a time frame, where you could get that person into a program sooner and get them better care. What happens is—I'm not sure what the past year statistics were but people waiting for the last 24 hours of a patient's life to refer or be admitted—you get some benefit out of it, mostly the family does, but it really doesn't solve the issue or the problem. So I think we need a review of the criteria for admission into hospice.

Another question I have about this history is, thinking of what are the right metrics for success for hospice and palliative medicine. When I think of when the Medicare hospice benefit was passed, part of my understanding was that it's going to be good care but it's also going to save money. But if you chose the wrong outcome it seems you're going to be graded on something that might not be in the best interest of the field. What do you think are the right metrics for success, for reimbursement, for whatever it is, for hospice and palliative care? And are those what we have in place now?

Donald Schumacher: The cost issue is something that really always hangs things up when they get to the conversation. Medicare every once and a while goes through this whole thing about "hospice is costing a lot more than we thought it would." The thing that they never do—they only look at the problem. They never look at the success of it. The success would have been to look at like a certain cohort of patients who receive hospice services and what it would have cost if they would have not received hospice service, but had done aggressive therapy for the last couple of months of their life. I'm sure the cost difference
of that would be considerably lower. But they've never studied that. I think that it's a combination of certainly the cost—ask me that question one more time, if you would.

When should be the good metrics of success in hospice and palliative care?

Donald Schumacher: Earlier referrals, like the length of time in a hospice program would be a good metric. Pain and symptom management; where was the pain and how were things effectively managed. The longitude and the effect of hospice care on the bereavement of the family and on the community that that family lived in. I think that looking at opportunities for always improving medical treatments, that would helping to reduce pain and symptom problems. More than anything I think would be, whatever is going on with that individual person that's receiving care, if they themselves and the family have agreed to a care plan that identifies what the direction of the care should be, and that people stick to it. Again if you don't have the advance directives when going into a hospital, as an example, all kinds of terrible things can end up happening to you when you never get your advance directives put on your chart. There are mistakes that I think do get made because I think there are still some loopholes in our system, but adhering to the care plan that the patient and the family have set up, I think is the most critical part. And I think this stands a lot of need for improvement.

So over your career, what have been the biggest changes from when your best friend died of leukemia when you were 19, until now? What are the biggest changes in the care that we provide for these kids that are suffering and dying?

Donald Schumacher: I think that if he would have been able to talk about it, that would have been the best thing that I think could have happened. Maybe—you know since 1969, there's been a zillion and one medical improvements in the treatment of leukemia, so that would be one thing. But in addition to that, the actual process of dying, he would not have been alone. Now I think we've done a really good job of making sure that the patient and the family are not alone. Again, if they want to be alone they can certainly be alone, but they don't have to manage this conversation or the experience of dying on their own without enough support. And I think that's been the biggest part of it, that's exactly the hospice, as the intention was in 1965; Cicely Saunders started doing what she was doing; Kübler-Ross in '69. The whole thing was about conversation and making sure that people have opportunity to say goodbye, to articulate their wishes and their needs. And to have their family at their side if they want them to be as the process takes over. That's been a huge improvement since we started in the early 1970s.
**Bryan Sisk:** The real on the ground launch of pediatric palliative care was taking root in the late 90s and then really took off in the 2000s, which is right around the time that the president and CEO of NHPCO created this sub-committee of palliative care, and kind of forcing a recognition of this need. So maybe a hard question, if had not become the president and CEO, what affect do you think that would have had on the development of palliative care at that time for kids?

**Donald Schumacher:** Well I think at the Academy of Hospice and Palliative Care Medicine, there were more and more pediatricians, folks who were trying to do this, but there were not organized effort. I think we helped to organize the effort, again, totally our responsibility of our success, it was everybody's success. But I think if we had not put our shoulder to the wheel we would have ended up much further behind than we are now.

Then beyond the concurrent legislation you got into the Affordable Care Act, what are the other biggest success that you think your work through all of these various organizations provided?

**Donald Schumacher:** The work in Africa. We did a lot of work in Africa. I raised a lot of money to send to sub-Saharan Africa to deal with the HIV and AIDs epidemic. The AIDs epidemic was, in terms of hospice care, was being effectively managed when I became president in 2002, but we were way behind in trying to help third world countries after this self-assessment. So we raised money and I hooked up quite a few hospices in the United States with hospices in sub-Saharan Africa. They raised money for their own program here than sent money for programs over there. Probably one of the best things we did in the country of Tanzania; there were no hospice or palliative care services, and we were able to get a big grant from, I forget where it was from now, but developed 17 hospice programs in Tanzania. That was a very big thing there was no hospice or palliative care, very difficult and painful. I think the long-term successes of change in end of life care and hospice comes from the fact that people are finally recognizing that it's a need that people have and the conversation about it can actually bring some resolution of the difficulty. I'm a clinical psychologist by training and talking about life is the number one thing that you do, but I do think that had we not put our shoulder work in, I think the conversation, and including in the conversation with the patient, I think we would be a lot further behind than we are now.

And where do you think the field of pediatric palliative care still needs to grow the most or strengthen the most?

**Donald Schumacher:** Probably in developing respite services for families. I think patients—it's hard taking care of a dying person, it's hard to care for a dying child. I think
respite services are really, really low on the trajectory and there's no real money set aside for doing respite care at all. So that's one big thing. And the ongoing training, working with the staff and the families to have the conversations, that where they have to keep—people will always retreat to being quiet when they're afraid of what's going on, so helping a conversation take place will help to reduce having some of the retreat away of what needs to happen.

Bryan Sisk: Conversely what do you think are the strongest areas of the field right now?

Donald Schumacher: The strongest area I think is there is more and more teaching and training education that's going on and people from the hospice and palliative care world, I think every hospice program in the United States—it's not every, but close to every, takes kids now and that was not the case when I started in 2002—the number was very, very low. So, I think that's the best and the brightest. It's not that as many people are afraid as they were in the past, which is great. It's still there, but it's not as prevalent as in the past.

Bryan Sisk: I'm getting to my last question, which is I would really love for you to dream aloud. If budget and politics and all of other obstacles we talked about, if none of those existed, what would you want care for these kids to look like ideally in 10 years?

Donald Schumacher: I would like for all the major pediatric treatment centers and hospitals around the country to have made a strong commitment to a hospice and palliative care policy in their system. And if they were as committed to providing the good conversation about hospice and palliative care as they are committed to providing good aggressive medical treatment, I think that the chance we have now going forward with this piece of legislation—and there will be others coming along as well I'm sure—it's the best chance for us to be successful is to not lose track of the fact that this has got to considered just as important as an aggressive therapy.

Bryan Sisk: And what do you think that commitment that you had hoped from hospitals, what would that look like?

Donald Schumacher: I think it would have been having things like, let's say when in the hospital and they're doing rounds or they're working on care planning for kids, if they bring in from the community the care provider, whoever will be taking care of that kid at home; I don't know how often that happens. When I was running the program in Buffalo, it's one of the things we did. And that was the hospice team went around to children's hospitals to make sure we were all planning together for that child to come home and work to care for him. I think those kinds of networking opportunities and not being afraid to have that
experience is the kind of we're that's where we need to go to build a strong and that will prevent us from sliding backwards.

[00:51:36]

_Bryan Sisk:_ Those are all the questions I have, but I'm interested, is there any other big area of this history, either your personal history or this history of the field that you think I've missed?

_Donald Schumacher:_ I think you've got it pretty much all wrapped up. The notion of encouraging people to get beyond their fear in taking care of this population is something that made a real big difference. I am very grateful to the pediatricians, and to the nurses, and to the staff, and all of in-patient hospital settings that took the risk of trying to having some of these things take place in the hospital and then having them discharged to home. I think the standard of care always will need to be tweaked and made better, but I say we really made a significant contribution to that process and that includes everybody within this field. No, I think you've done a great job.

[End of Audio]