Voices

by Joe Keiderling
Keynote for Schuchmann–Rifton International Export Meeting
27 June 2024

As I have watched the presentations and training sessions of the last few days I've found myself marveling over the place we find ourselves in today. The history of advocacy for children with disabilities is long and often appalling. In the United States it goes back well over a hundred years. Schuchmann and Rifton are only two small players in the grand arc of this history as are each of you from your own countries. But how privileged we are to follow in the footsteps of brave people over the years who dared to speak out on behalf of the people without a voice among us. I think it's a good thing, every now and then, to reflect on our place in this greater story, on how far we've come. We do this to gather strength for the challenges that still lie ahead, and God knows they are many.

I only have a few minutes today, so I can't tell as many stories of these voices as I should. I can only draw attention to a couple. And my stories are purely American because that's where I'm from; each of you would have equally compelling stories from your own countries. But let me tell about the American author Pearl Buck who, in 1931, wrote the great classic novel of life in China called *The Good Earth*, a book which made her famous and, seven years later, won her the Nobel Prize for literature. But what is not well known about Buck is that she had a daughter named Carol who was born disabled. In fact, it was partly concern over her daughter's future that led Buck to write *The Good Earth*, in hopes of earning some security later in life when she would be unable to provide for her daughter. In a letter to a friend while Carol was still a child, Buck wrote of her pain over her daughter's condition and her uncertain future. She writes:

> It is not shame at all but something private and sacred, as sorrow must be. I am sore to the touch there and I cannot endure even the touch of sympathy. Silence is best and far the easiest for me. I suppose this is because I'm not resigned and never can be. I endure it because I must, but I am not resigned. So make no mention of her and so spare me.

This private shame and the silence that surrounded it was, tragically, all too common during the last century. And in many countries around the world it is still far too prevalent today. But to Pearl Buck's enduring credit, she rose above that shame and, in 1950, wrote a small, beautiful memoir about Carol called *The Child Who Never Grew*. It is a deeply affecting and poignant portrait of mother and child. And it shares with remarkable candor what a parent goes through when she discovers that her child is "not normal" and will have special needs all her life.

Parents of a child like Carol are often possessed of an intense desire to bestow meaning and purpose on their child's life, to make sure that others take notice. This was certainly true for Buck, and through this book, many did take notice. It drew an immediate outpouring of gratitude from parents all over the world, and I think Pearl Buck helped the world take one step closer to a healthy respect for children with disabilities and their families.

In the United States, starting in the late 1800s, the model for care for people with any kind of disability – mental, intellectual, physical – was hopelessly, tragically, inadequate. It was charitably referred to as "institutional custodialism" but it was really just warehousing, with thousands of people confined in subhuman conditions of neglect. This model arose from that same sense of shame that Pearl Buck spoke of, and it was through voices like Buck's that light was cast on this deficiency in our society, declaring that disability is not a mark of shame but a challenge to all of us to create opportunity where none

exists. But it took many voices, bravely speaking out against the culture, speaking for those with no voice, that gradually led to change.

Yesterday Jörg recounted the stories of other voices in America; I'm sure he mentioned the Kennedy family, whose sister Rosemary exposed them to life with disability. He probably mentioned the TV journalist Geraldo Rivera whose exposé of one huge state institution – Willowbrook – shocked the country. There was also Franklin Roosevelt, himself crippled by polio, who ignored the social stigma attached to disability to lead the United States through some of our most challenging years. Each voice combined eventually to form a chorus of protest that led to change. All of us here in this room owe a debt to these voices.

It was this chorus of protest that lead to a watershed in American history, which Jörg also referred to yesterday. In 1975, the U.S. Congress passed a law establishing a right to education for every child in the country, regardless of ability. Overnight, the appalling system of hiding children in huge, filthy state-run institutions was declared unacceptable. It forced public schools to find accommodations for kids with special needs. This law was called the Education for All Handicapped Children Act of 1975. That was when another company, Rifton's older sister, called Community Playthings, started getting requests for customized seating to accommodate these newcomers. This, in turn, gave birth to a new company that was called Rifton.

But what propelled all these voices was the conviction that people with disabilities have a vital contribution to make to our society; they saw how we deny them this contribution because we don't welcome them, we refuse to embrace what they have to say to us. We are ashamed of what we perceive as weakness. For this, society is poorer. We will not become the society we were meant to be until every member, regardless of ability, is provided the tools and the care to fully participate.

Talking about disability advocacy is fraught. There are voices among people who are actually physically disabled themselves who have spoken eloquently about the paternalism among the rest of us who think we know what's best for them or who try to speak on their behalf. So I have to be careful here how I choose my words. But there are others who are both physically *and* intellectually disabled who cannot speak, and who rely on advocates such as those of us gathered here today, and I think I can speak on their behalf because I have a personal connection. There is a woman in my household who is both physically and intellectually disabled; my wife and I have made a home for Kathleen for the last five years. I would call her an adopted daughter except she is only a year younger than me. She has a rare genetic disorder that has caused a host of associated problems including significant neuropathy of her hands and lower extremities causing, in turn, atrophy of her hand muscles, disfigurement, and an abnormal gait. She also has premature aging and an increased risk of infectious disease, seizures and significant mental disabilities including bipolar disorder, OCD, anxiety and early dementia. She is at once a challenge to our patience and a perfect guide into her world of disability. So when I speak about advocacy I always have Kathleen to keep me grounded and real.

A wise man once said, "My strength is made perfect in weakness." This is usually understood to mean that a person's character is improved by the suffering or the imperfection he endures. But I think it applies equally to society. So I'll repeat what I said earlier: we will not become the society we should be until we celebrate all our members, in all the wonderful variety of our abilities and disabilities. What we perceive as our defects are actually our strengths. What we consider inarticulate can actually be profound. In the small community where I live, Kathleen provides an essential element and contributes to the whole in ways that I never could.

Today, advocacy for people with disabilities takes on different forms depending on where you're from. Your struggles in your home countries might be different from mine. I can tell you that for us in the United States today, advocacy means fighting for adequate health insurance coverage so that people don't need to wait eight or ten or twelve months to receive life-changing equipment. It means fighting to remove the repeated denials of coverage, or the indignity of trying to prove that standing is important for your health.

For Rifton, from our first days we knew that to produce equipment that would really make a difference for these special kids, we would have to truly understand their lives and their challenges. We'd need to see their homes and their classrooms, talk to their parents and their caregivers, understand the medical complications that seemed to define their lives. In other words, *we had to care*. Over the years we've seen companies come and go in this space. Some seemed opportunistic, some even predatory. In our experience, only those that entered this market because they cared were able to survive and grow. That's why we were drawn to Schuchmann, already back in the late 1990s, when we were looking for a European partner. We needed a company that cared, a company with heart. In the years since we have never had reason to regret our choice. Schuchmann has admirably represented the Rifton brand throughout Europe, and we're proud to consider ourselves partners in this important work we share.

Our alliance with Schuchmann has, in turn, led us to each of you represented here in this room. We consider ourselves most fortunate to be allied with you, and our challenge today is the same as it has been for decades. Together, we are to give voice to those who have no voice, either because they literally cannot speak or because their disabilities have robbed them of the dignity and respect and the access they deserve.

I want to end with one more voice. This one is contemporary but it represents one more piece of this great arc of history. In New York I have a colleague, Sam Durgin, who is himself disabled from birth. Today he is a product designer for Rifton. I asked him if he might contribute to today's keynote and he was happy to share his perspective.

Video Clip: Sam Durgin, Rifton Product Designer, 4:14
https://youtu.be/7rOYbEvVyyo
[To download: https://we.tl/t-dka3I2F6ri]

Sam is not here with us in Bissendorf, but I felt his voice was needed today. Let's remember that message of his, where he talks about the lines we draw that limit children; he said, "we need to inspire each other to move that line." That is why we're all here today, to keep trying to move that line. Thank you, Sam.

In closing, let us take a moment to celebrate our good fortune to be partnered with a company like Schuchmann. Our hosts, Torsten and Miriam, and their extended family here understand the need for advocates. They are uniquely sensitive to the needs of a family with disability. And we are so fortunate to collaborate with you in this important work. To you personally, Torsten and Miriam, I say thank you. The rest of us come from over twenty countries around the world on four different continents. As we head back home today and tomorrow, united as we are in this noble work, let us continue to speak out in defense of those whose voices have been muffled or silenced for too long.

Thank you to each one of you for coming.