Hi, my name is Delma Boyce, and I’m the mother of a 32-year-old, obviously I was very young when she was born, 32-year-old daughter who has been diagnosed with deafblindness. I’m also a teacher in the deafblind department in Perkins School for the Blind and have been for the past 26 years. But it’s in that parent role, as a mom, that I want to speak to you today. And forgive me for reading. If I get nervous, I will start to read, and I hope that’s okay. I have my notes with me, and it’s a little unusual for me to be talking to a camera, so forgive me if I get nervous and start to read.

On a rainy Sunday afternoon 32 years ago, my life took an unexpected turn. Her name is Dolly. She has bright red hair, blue eyes that have to work hard to focus, and ears that just refuse to hear no matter how many things we stick on them or in them. I had Rubella, also called German measles, in the first trimester of my pregnancy. For the first 6 weeks after Dolly’s birth, everything seemed well. Then at her 6 weeks check, it all began. Cataracts that required multiple eye surgeries. They didn’t have the beautiful techniques for cataracts back then that they have now. She had a total of 6 surgeries for each eye. She has profound deafness, severe developmental disabilities, heart defects, urinary tract malformation, on and on and on. Seemed everything we took her to the doctor we discovered something new.

She’s worn a great many labels in her life – deafblind, mentally retarded, developmentally disabled, brain damaged, so forth and so forth. At what time she was thought to be emotionally disturbed, because of her severe behavior problems, until a wonderful psychologist, who became an instant friend, said she thought she was not so much emotionally disturbed as she was emotionally disturbing. We’ve had many occasions to remember that label and smile.

The journey that began that Sunday afternoon so long ago has brought Dolly to a group home in Littleton, Massachusetts, and it’s brought me to talk to you today. Except for a twist of fate, I could be sitting where you are, and you could be where I am – trying to tell the lessons of over 30 years in one brief span of time in one afternoon in March of the year 2000. I’m just like anyone else, but with a difference – a difference that all parents of disabled children share. Life has hurt someone we love, has harmed our families, wounded our spirits, and forever changed the direction of our lives.

I just remember being breathless with pain and fear in those early years. The jargon of the various disciplines alone was enough to intimidate a young mom. We saw a variety of specialists – physical therapists, occupational therapists, audiologists, ophthalmologists, neurologists, psychologists, cardiologists, more “ists” and “gists” than we knew existed. And diagnoses – ever changing, ever increasing diagnoses. The ophthalmologist gave us little hope for her vision. It is one of the great joys of my life to tell you he was wrong. Her vision is far from perfect, but she
has beautiful blue eyes, and those eyes see. Those early years especially were terrifying times as a
variety of people – some kind, some abrupt, some comforting, some not knowing how to give
comfort – told us news that no parent should ever have to hear: heart malformations – cardiac
jargon, urinary tract problems – more new jargon, intellectual testing, hearing tests, eye surgeries
– jargon, jargon, jargon. Our hearts broke as our vocabulary grew. By the time we got to caring,
supportive, knowledgeable people, we were hurt, wounded, bitter, and angry – trying hard to do
what was best for Dolly and not always knowing how. How we got from there to here is the
journey that gives me the right and the privilege to be here speaking to you today. If anything I
say reaches just one person, and educates, informs, enlightens, or just lightens a burden, our
journey has not been in vain.

Remember when I mentioned that except for a twist of fate anyone could be the one sitting here
today, we parents of disabled children are just like ordinary people who find ourselves in
extraordinary circumstances. It can happen to anybody. Consider: some are young, some are old,
and some are in-between. We come in different sexes and in many sizes, shapes, and colors. We
come from different ethnic backgrounds, socioeconomic levels, spiritual persuasions. Some of us
are married; some are not. Some are rich; some are poor; most are in-between. I’ve already told
you that I’m an educator; I definitely picked that in-between category. Some are easy to talk with
and easy to get along with, and some are not. Some have a great sense of humor and a great deal
of understanding, and some seem to have no sense of humor or understanding at all. Some are
healthy in body, mind, and spirit, and some are not. Some are very demanding; some are easy to
please. All have felt alone at times, betrayed by God or fate, misunderstood – feeling that they’re
the only ones in the world who’ve ever felt the way they’re feeling. Sound familiar? If you didn’t
already know who I’m talking about, what group of people might you think this is? Almost
anybody. Parents of children with deafblindness are ordinary, everyday people – people with
dreams, hopes, aspirations, disappointments, imperfect people – just people. There are no perfect
parents, because they are no perfect people. We make mistakes – we say things we shouldn’t
say; we do things we shouldn’t do – just like everybody else. We wallow in guilt over things that
we’ve done, and then we wallow in guilt more for things we think we should’ve done that we
didn’t. There’s no training to be the parent of a child with deafblindness – no course work, no
college work, nothing. This job usually comes as a complete surprise, and it’s all on-the-job
training. We didn’t choose this career; there’s no time to think about it. We can’t change our
majors. Some parents feel blessed, special, chosen by God for this special job; some feel cursed
by fate, singled out. Most of us, I suspect, at one time or another, go through stages of both.
And parents have a role outside their role as a parent of a child with deafblindness. I’m many
things; I’m not just Dolly’s mom. There are many parts to my life. I’m an individual in my own
right – I’m somebody’s daughter, somebody’s wife; I’m a fiend, teacher, a musician; someone
who loves books and yellow daisies and the Atlantic coast of Canada.

There is life outside my parent role; however, since I’m here today in that role, let me share a little
more of my parent heart and mind with you. These are a few of the things I ask professionals
who work with our children to consider:
• Please keep their environment clean and safe.
• Protect them from those who might harm them. My daughter is so vulnerable, it scares me half to death.
• Please keep them safe. Dolly doesn’t know about the dangers of this world. Keep them safe.
• Consider their dignity please, and keep them with respect. Bathroom and bedroom doors should be closed during private times. Our children’s lives are not to display.
• Consider their health. They often cannot tell you when something is wrong – when something is hurting. So be vigilant and caring.
• And consider their appearance please. Life is challenged them enough. Do not draw further attention to them by having them look less than their best.
• Consider their need to be loved and accepted just for who they are. After all, isn’t that what we all want and need?
• Treat Dolly well. Treat all the Dollys well. They are very precious to us. Treat them well.

The last thing I want to talk to you about today will be a very familiar topic – communication, and it’s way at the top of list of things we all need to know as much about as we can if we’re to best our deafblind children learn and grow. Never ever let anyone at anytime – I don’t care what their degree is, what their stature is – don’t let anybody tell you that any child cannot communicate. No matter limited a child’s abilities may be, he or she can communicate. You simply have to find the way. We need to learn all that we can and then keep on learning. I’ve been teaching children with deafblindness for 26 years, I’ve been Dolly’s mom for 32, and I’m still learning everyday from my students and from my daughter.

Years ago, I made a sleeping child a promise – a promise that I would never speak to a group without trying to be her voice and tell her story. Dolly doesn’t know I promised; she doesn’t know what a promise is, but I know. What I’m about to share with you now was written several years ago when Dolly was in a place not quite so lovely as she is today. It was a plea for understanding and acceptance of her need to be included – to be a full member of the world she lives in.

Take a journey now with me. Think of a world mysterious, strange, confusing – a world ruled by foreigners. You can tell they’re foreigners, because they don’t speak your language. You’ve tried signs, gestures, behaviors – they didn’t get it. They’re definitely foreigners, and they’re very powerful. They are definitely in charge. These rulers from a foreign land make you get out of bed without talking to you at all. They help you shower and get dressed, all the time talking to the other foreigners but not to you. They make you brush your teeth, brush your hair. Then they sit food in front of you without telling you what it is. It’s not foreign food, though, you’ve seen it before. You wonder, maybe, it just doesn’t have a name. They continue to talk to each other for a while, in that foreign language only they can understand. Then suddenly one of them signs to you, “Clean up.” And, wow, you get really excited. Maybe they do know your language. So you sign “more,” because you’d really like some more to eat. One of the foreign rulers signs
“finished,” and because they’re the rulers, you have to be finished. How come when you sign, you don’t get what you ask for, but you have to do what they way when they sign? It can all be very confusing.

And who are they anyway? They’ve worked with you before, but you don’t know their names. Do they have names? Or maybe they just didn’t tell you, because someone said you were low functioning and wouldn’t understand anyway. I wonder how they could know that when they don’t really know your language. They seem to have a few words in sign, but not enough to really understand you at all. And, you wonder, do they know you have a name? You’ve never seen any of them use your name sign. You don’t know how to tell them your name, but you understand that your name sign is you, and you sure wish someone would tell them your name, because without a name you’re just kind of anonymous – a generic deafblind person they’ve been hired to work with.

That foreigner over there didn’t even say hello to you when she came to work. She just chatted with the other foreigners and then turned on the television. You really wish, if they were going to work with you and your house mates, they’d learn to communicate with you. Maybe it should be a rule that if they’re going to work with deafblind people they have to learn to sign. Everyone’s lives would be easier. Your needs and wants could be better understood. You’d be calmer, happier; you’d feel better about yourself. You’d like the foreigners better too, and their lives would improve. Your behavior would improve; your job performance would improve. It’s a fact. Past data on you and others prove it. You’d love to be able to communicate with these foreigners. You see them all the time. If they could only speak your language, they could get to know you better.

Because they don’t know you really, they don’t know you can be so much fun, that you have a great smile, an infectious giggle, and the irresistible charm of a 3-year-old woman-child. They don’t know yet how much they can teach you – how much fun it can be, how loving you can be when you’re understood and accepted, how much you need them and how much they can learn from you. They don’t know how rewarding this job can be – how important and terrific they’ll feel when they see you grow and learn – when they can talk to you and you to them. They don’t yet know that anyone can learn, anyone can grow. They don’t yet know that they can look back with a sense of accomplishment and joy and satisfaction because they’ve learned to communicate to you and with you and together you’ve built trust and ability and an atmosphere where growth and learning can take place for everyone.

Dolly Boyce, all of the Dollys in this world are worth every effort – all the work, the unspeakable pain, the indescribable joy – worth all we’ve faced on the journey of her life to her and beyond. Our children need us to care enough to learn their language – their communication in all of its complexities, twists, and turns. It’s a daunting task – an ongoing, ever changing, ever growing task, and it requires care and commitment. We need caring, competent communicators on our journey. If Dolly could talk, she would say these things to you. Because she and her fellow travelers do not have the voice to tell you these things, today I lend them mine. I know that if
they could, they would tell me to tell you how much they need communication – how important it is, how it’s a life-altering basic human need. Consider yourselves told.