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KEYNOTE ADDRESS

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I don't know much about how to catch monkeys but I have heard a story about how it is done. You take a coconut, and make a hole in it just large enough so that a monkey can squeeze its hand in. Next, you tie the coconut down and put a piece of candy inside. The monkey smells the candy, puts its hand into the coconut, grabs the candy and then finds the hole is too small to get its fist to get out. The last thing the monkey would consider is to let go of the candy. Often they let go when they fall asleep or become unconscious because of exhaustion.

When I told this story to Jill, a woman who had lost her hearing several years ago, she gave me the same quizzical look that some of you are giving me now. I could imagine a group of monkeys sitting together at a seminar entitled "How To Avoid Being Caught By Humans." Their advice might be as follows: If holding on to candy causes you to be trapped-- for God's sakes, let go of it. Because ultimately, it is the monkey's unwillingness to let go of the candy that is the cause of its suffering.

We all have attachments; many of them are quite healthy. We are attached to our partners, our children, our friends, and perhaps an idea, a God, certain clothes, music. The Peanut character, Linus, is attached to his blanket. But most of all we are attached to our own identity--our perception of who we are.

Even though Jill had been deaf for several years, she was firmly attached to her identity as a hearing person. In essence, her identity was that she was a hearing person minus her ears. Her mother taught her what would become an ingrained mantra—that if you want to, you can. One of her memories was the train that couldn't make it up the hill until he put his mind to it. But no matter how much Jill tried she couldn't make her ears work. She described herself as a square peg in a round hole-- or with pejorative words such as incomplete and

inadequate and she was barraged with shame. I know I have to accept myself, she signed to me, knowing that, like the monkey who didn't let go of the candy, she would suffer if she didn't let go of her hearing identity, and got a new deaf identity. From a distance it looks so easy.

I've been privileged to have worked with many persons with hearing loss who have experienced this kind of transformation. One of the principles I've learned is the necessity of letting go of what is familiar to the hearing world in order to attach to what eventually will become familiar in the deaf world.

But if you think about it, isn't there a moment in time when one is no longer hearing but not yet deaf—a time when you are no longer who you were but are not what you will be? There are many examples of this in-between state: Getting married. Before the ceremony, I was single. Immediately after saying "I do," I was married, done deal. But to most of us there is a period of several months when although we are no longer single, we don't yet feel married. When you turn 21, although you are no longer a child, you don't yet really feel like a real grownup. When you move to a new residence, you no longer belong in our old house but neither do you really feel like you belong in your new house. We don't even have to restrict ourselves to humans. We know that in the case of caterpillars, for example, at some point they turn into butterflies and shift identities. Think about the point in time when the caterpillar is no longer a caterpillar but is not yet a butterfly. The in-between experience is certainly endemic to hearing loss.

Social worker Holly Elliott, who became deaf, described her feelings about being between the hearing and deaf worlds. "Hearing people often think I'm hearing because my speech is good. Deaf people often think I am hearing because my signs are bad. We are caught between incomprehensible speech on the one hand and incomprehensible signs on the other."

I will never forget my first time when I worked with a hard-of-hearing adolescent 25 years ago. Prior to that I only worked with culturally deaf people in Boston. She told me, "Nobody understands me. Nobody takes my unique condition into account." I asked her to tell me more. I listened. "You don't get it, Mike." "Tell me more," I would say. "You just don't get it," she would repeat. We were going round and round in circles. I must admit, at this point I thought to myself, what adolescent doesn't feel this way. For that matter, what adult doesn't? We were stuck. One day I was setting up a conference and the brochure for it read: "For deaf and hard-of-hearing and deafened people."

The brochure went out and I got a phone call from guy that ran a hard-of-hearing agency for deaf and hard-of-hearing people. He said that the brochure looked good and asked confirmation that ALDs would be used. "Right, right," I answered. Afterward I walked over to a colleague, and asked him what an ALD was. Then I met once more with Mary, who again told me that nobody understands her unique needs. But this time her therapist, namely me, finally got it. So I asked her to stand up with her arms outstretched and make one side the deaf community and the other side the hearing community, and go back and forth. For the first time, knowing that I understood, she began to cry. She talked beautifully about how on one hand she felt deaf--because like all deaf people she was outside the hearing world and

knew what it was like to have a hearing loss, what it was like to be isolated. She didn't fit in. She didn't sign ASL and didn't feel like them, so she must be hearing. But when she's in group conversations and can't follow what is being said, she felt there is a glass wall between herself and everyone else. So she didn't feel hearing either. She felt stuck. Like Jill, the woman I told you about at the beginning of this talk, she wasn't hearing but also wasn't deaf in her mind.

Let's get back to Jill. Jill was impatient for change. As a busy executive in a high-pressure sales job she had no time to "dilly-dally," as she put it. She requested that the transformation of her identity happen posthaste. Nothing against grieving, she thought, as long as it can be scheduled at a convenient time.

Sure enough, a couple of months later she appeared in my office, not lost in pain but exuberant. She had, tickets for "Children of a Lesser God," had joined N.A.D. and SHHH, had joined several related on-line chat rooms, subscribed to publications, bought videotapes on signing and deafness, was taking signing classes twice weekly, one for ASL and one for PSE, was regularly attending deaf community events, was writing an article and was advocating for deaf rights. She pronounced herself reborn as a deaf person.

Something didn't seem quite right. It seemed too easy, too hurried, too much like TV, when everything works out by the end of the last commercial. It has a managed health care dream come true.

Soon after that, my wife and I vacationed at a lodge in Sedona, Arizona. It featured a huge outdoor labyrinth. Essentially the labyrinth consisted of several hundred pebbles placed on the ground forming a series of concentric circles. What you do is start walking from the beginning of the labyrinth and follow the trail of pebbles round and round in different directions until eventually you reach the center. Now, you can easily cheat by taking a shortcut and walking over the pebbles. You could reach the destination in seconds, saving the required 15 or so minutes. Frankly, I was tempted and might have done so if my wife had not been eagerly following the path. So I followed the path, but did it quickly. I made a beeline to the end at lightning speed to be sure not to waste any time. And as I did so, I thought of my meeting with Jill. Perhaps Jill, like me on the labyrinth, was making a beeline to a deaf identity at lightning speed.

The author John Steinbeck wouldn't have raced through the labyrinth. He had a better way in life. "In Travels With Charlie," he chronicled his cross-country trip with Charlie his dog. Although his final stop was to be Chicago, that wasn't his goal. His goal wasn't to finish the journey. It wasn't to arrive at the destination. It was to appreciate the ebb and flow of the long exciting unknown adventure.

So the \$64,000 question was: Had Jill in fact successfully let go of her hearing identity and adopted a deaf identity? Was I being an overly negative and pessimistic psychologist by doubting her happiness and passion? Some answers came soon enough.

The next week she was late for her appointment, which was very uncharacteristic for her. In answer to my concern, Jill told me that she had been bedridden with a bad case of the flu, unable to lift her head off the pillow. I asked Jill to describe her thoughts and feelings during this long week. She told me she had felt utterly terrified and helpless and that old feelings had come back making her feel lonely and sorry for herself. "I don't have enough words to explain that week. I was in limbo, in a void, and it was as if my life was put on hold." Jill, like many of us, minimized the benefits of not being outwardly productive. But difficult as that time was, there was a lot of internal productive work going on within her during that time. It wasn't just a pause as with a VCR. It felt like a pause only because she didn't have enough words to explain her in-between experience.

There is a Buddhist saying: "When the student is ready, the teacher will come." Jill would never have wished herself sick, but in fact, that week would have been the first of several similar times when Jill would experience this limbo, this void for which she did not have enough words to describe, and which we now understand was the experience of feeling no longer who she was but not yet who she would be.

So this limbo is such a great opportunity. We need more words to describe it. Instead it has been defined by what it is not: Not hearing, not just deaf: not a caterpillar, not yet a butterfly. We are very clear about what this in-between state isn't. But what exactly IS it? Mythology provides one answer.

In most cultures there is a myth that has a common story line and goes something like this: A hero grows up in comfort and security. But at some point he leaves or loses all that he possesses and perhaps becomes lost in the forest or some other strange terrain. There is danger at every turn along with hunger and deprivation. He becomes consumed with loneliness, fear, depression, anger and despair. Time passes, but at some point he is transformed and returns home. Although everything there is the same, he has adopted a new identity, and attained wisdom. This is referred to as a hero's journey.

You are on a hero's journey when you are no longer who you were, but not yet who you will be. By definition, it implies uncertainty, anxiety and fear. There is a story about a guy hiking in the mountains of Montana. He was awed by the wilderness and wildlife and when he met the park ranger, he asked if there were many bears about. "Sometimes," was the reply, "we get quite a few, in fact." "How about on that easy trail round the lake over there?" the man asked. "Any chance of running into any bears this morning so near the store?" The ranger paused long enough to hear the question behind the question, took a slow sip of his coffee, and replied, "If I could tell you for sure there wouldn't be any bears, it wouldn't be a wilderness, now, would it?"

Maybe that is what it comes down to. You can in life walk in what's predictable or enter the wilderness. The good news about a hero's journey is that you don't necessarily need to physically go anywhere and you don't need to face real bears. For Jill, her journey was being sick in bed with the flu. For this was a time when she was engaged in the uncertain task of figuring out who she was. For hearing and deafness, during that time, there were not enough words to describe what was happening. For example, she knew that with better hearing aids

or maybe a cochlear implant, that she could perhaps hold on to her hearing self and or she could choose to embrace the deaf world. This time would be the first of many such times when she was in an unknown zone, a psychological place where there might be scary bears. Her task was to honor the process of becoming, and to honor the journey between knowing who she had not yet become.

Twelve step programs teach this lesson well. They don't speak of having recovered. They speak of being in recovery. You are not self-actualized but self-actualizing.

So I come to you during this speech, not as one who has personally experienced this hero's journey, as I don't have hearing loss, but as a storyteller; as one who has had the privilege of bearing witness to the tales of triumph of this journey. To be frank, after doing this kind of work for 25 or so years, I find myself right now knowing that I have many more questions than I have answers. Certainly many more questions than when I first started out. I have good days and bad days and I have learned to be clear for the most part about what form a hero's journey may take. I don't pretend to know the best way. What seems quite clear is that any journey requires navigational tools like a compass to make sure you don't get lost.

Let me spend a few minutes describing tools. First tool is finding vital threads of continuity. A 60-year-old man who lost his hearing once told me that, although he had had many challenges in his life, becoming deaf was like nothing he had ever experienced. "My wife loves to socialize," he said, "but it is impossible for me now to function in social settings. What do I do? How do I adjust?" I asked him whether there was anything he had learned from those other challenges in the first six decades of his life that could help him now. And after a few moments he recalled when he first learned to ski. He was absolutely terrified, he said, just looking down that huge mountain. "What did you do," I asked? "Well, at first I just stood there and was going to chicken out," he said. "But all my friends were watching. So I took a deep breath, prayed, and focused on the immediate task. Then I went down that mountain very slowly, trail marker by trail marker."

We then discussed the huge mountain of hearing loss, how he had to let go of his hearing self and begin a hero's journey toward adopting a new self. I wondered aloud to him whether it might not a good idea to break up the task of attending parties with shorter sprints. I read to him a quotation by Mary Kathryn Bateson, a cultural anthropologist. "Much of coping with discontinuity has to do with discovering threads of continuity. You cannot adjust to change unless you can recognize some analogy between your old situation and your new situation. If you can recognize a problem that you have solved before in a different way, you have a much greater chance of solving that problem in a new situation."

So later that week this man metaphorically began skiing down past the first trail markers. He showed up at a party with only a few people, and he found a vital thread of continuity between how he had once overcome the challenge of skiing and how he could learn to cope with his new situation.

Another tool: Know that some parts of the journey must be done alone and some must be done with somebody else. Let me tell you the story of Carol. "About 30 years ago," she told

me, "I had just turned 21 and was driving around with friends one summer day. We were stopped at an intersection when a drunk driver hit us head on. I woke up in a hospital, having been in a coma for several days, and found out that all my friends in the car had been killed instantly. I very clearly remember lying there, watching people's mouths move but being unable to hear their words. My hearing was completely gone." She went on to tell me about how her parents helped her. She took a year's leave of absence from college to recuperate, living at home with her parents and going to rehab as well as to a host of doctors. "I remember when it first really hit me that I was deaf and going to be deaf forever. It was in the middle of the night about a year after I had left the hospital. A terrible nightmare about suffocating in a plastic bag woke me up. My heart was pounding and my whole body was covered with sweat. Without any hesitation, I immediately went to my parents' room, like I was a little girl again. For a second I stood there noticing how soundly they were sleeping and how peaceful they looked. But there was no question in my mind that they would want me to disturb them. So I shook them out of their sound sleep and told them about my nightmare. We all knew what it meant. My mother held me. I felt her body spasm and they both began to cry. She began to stroke my hair. My dad was sitting up in bed with one hand on my mom's shoulder, the other hand on mine. I felt very close to both of them that night. None of us got any more sleep and as the sun rose, my dad suggested we take a walk. I walked between my parents, hand in hand, just like I used to when as a kid. The sun came up over the trees, through the mist, exploding colors through the woods. We were quiet for a very long time. My dad was the first one to break the silence. As we sat down on some rock he said gently and lovingly, "You know, Pumpkin," my pet name, "you will get through this. You are going to have a full, happy and very successful life, but not without some pain, and you never have to shut us out from that. We all began to cry again and we sat there for a very long time. It was then that I knew that everything would be okay."

Amazing story, isn't it? And we can have this support even when another person is not physically present. Two months after 9/11, a Boston based American Airlines flight attendant required psychotherapy. She hadn't been to a therapist since she was ten years old when her mother had passed away. But now she told me that she had been brutally awakened every night by nightmares and explosions. Obviously no interpretation is needed. She felt alone and scared. Her best friend had been trapped on that fateful flight and her post-traumatic symptoms began several days afterwards. Among other things, I asked this woman if she had talked to her mother about her nightmares. She gave me a curt and angry look and said, "I told you my mother is dead." I replied, "I know, but maybe, just maybe you can still talk to her." About a week later I got an E-mail from this woman, which I would like to read parts of to you.

"Dear Mike," she begins, "I feel silly writing this, but I have been talking to my long deceased mother almost every other night. When I'm up at night by myself thinking about how our world has changed I think of my mom and I in the kitchen together. Last night I asked my mother, "Do you remember when Johnny called me ugly? You hugged me. Then you made caramel apples and let me eat one after I had brushed my teeth." I smile every time I recall that very special night." Alongside the unfathomable horror of 9/11, that flight attendant could visualize that special night with her mother. That was an essential tool for her hero's journey. Some of you have seen the movie "Cast Away", with Tom Hanks, whose

plane crashes on an island. He found himself without a future, far from civilization. He shouted, hoping someone would hear him, and when he realizes he is all alone, he paints a face on volleyball and names it Wilson. He talks out loud to it and imagines that Wilson is talking back to him. He even, at one point, risks his life to save his volleyball.

I also have had imaginary dialogues in my writing. I'm alone in my office and I type a bunch of stuff on my computer and imagine how you or others will respond. I go back and forth all day with these imaginary dialogues. It is an essential part of my growth.

Jill also spoke about the value of relationships for her growth. She was single and she was telling me one day that she had moved into a housing development. She said, "You know, I have more fun than anybody else being a single person. All the other people were married and paired off and argued about the color of the walls, rugs, counter tops. I can choose any color I want and have a great time." "But," she added, "I did not learn as much as they did." A wonderful lesson, how growth happens when we share our lives with others in addition to ourselves.

Another tool: Know that one successfully adopts a new identity by realizing this is impossible. Let me repeat that. Know that one successfully adopts a new identity by realizing that it is impossible. Let me explain. I don't know about you, but I think new identities are overrated, or at least misleading. The part to believe (Mike something seems wrong here—can you fix it? Or am I not getting it CP) is that with enough work, one can drop one identity and take on another, like my car mechanic replaced my old transmission with a new one. Indeed, after I told Jill how to catch a monkey, she did not recognize the intended lesson. Namely, just as the monkey holding on to the candy caused its suffering, Jill holding on to her hearing self for so long caused her to suffer needlessly. That story, by the way, is a Buddhist sermon that a colleague, Randy, was kind enough to send me. I certainly don't have the wisdom to dispute a Buddhist teaching and in fact I agree with it in principle. It is not that I think a new identity is a bad idea or untenable but that it is oversimplified. There is an old saying that the map is not the territory. Although a map is useful to get us from Point A to Point B, the map does not portray the complexity of the terrain. The construct of adopting a new identity in a hero's journey is useful as a guide, a map, but like any construct, it doesn't do justice to a very complicated process.

I am reminded of a 40-year-old woman who had had a profound hearing loss since late childhood and opted for a cochlear implant one year ago. As she put it, "Since my cochlear implant I am more hearing now than I have ever been, but in some ways I'm more isolated than I have ever been. I feel I cannot tell my deaf friends truly what's going on in my life as I am embracing the world of sound, hear the wind in the trees, the sound of a kiss, the laughter of somebody over the phone as I take my place again in the hearing world. Just as hearing people cannot fathom the grief of being separated from their world they cannot understand the world of hearing. If I had lost a leg, and had it replaced with a wooden one, nobody would imagine I was made whole again. Yet with an implant, they do and I feel I have lost them."

Let me tell you about another story, about a man who suddenly lost his hearing on Christmas morning several years ago and who has since then, relived that trauma every Christmas. In his words: "Christmas was stolen from me." He felt tortured by every joyous holiday reminder. The more he tried to move on and find happiness, the more his hearing self would intrude and the more frustrated and despairing he would feel. On the next Christmas Day he agreed to do the following: He would continue his tradition of opening presents with his family, carving the turkey, and forth, but he would also reserve at least 15 minutes to be by himself and feel sad, to grieve, and to revisit his old hearing self. At some point during the day he would announce this to his family and request that he not be disturbed. And an amazing but not surprising thing happened when he allowed himself this ritual. He found that when he acknowledged and honored his tortured past, he was able to enjoy his present and new self with his loved ones. And every Christmas he would repeat this hero's journey, taking a short leave from his deaf self and revisiting his earlier loss.

Tuesdays With Morrie by Mitch Ablom is a wonderful book. The author chronicled lessons learned about life from his teacher who was dying. One day Mitch asked his teacher if he ever felt sorry for himself. "Sometimes in the mornings," Morrie said, "I give myself a good cry if I need it. But then I concentrate on all the good things still in my life, on the people who are coming to see me and on the stories I'm going to hear. I don't allow myself any more self-pity than that. A few tears each morning, that's all. Then I look forward to the day."

Shifting identities is more complicated than it first appears. I very much do believe, as Jill put it, that we humans have the capability of being reborn. But on a deeper level, perhaps we are continually in flux. Maybe we continually cycle back and forth between who we were and who we are, like the Christmas story and like Morrie allowing himself a few tears every morning. Jill used a different metaphor. She said, "I continue to hear deaf voices and hearing voices in my head. The deaf voices remind me of what I can look forward to. They give me purpose. They ease my loneliness and give me comfort. The hearing voices remind me of my loss."

Although Jill decided to adopt a deaf identity, the internal voices from her old hearing self didn't just go away and disappear. But they no longer occupied center stage. They became just one of many new internal voices having to do with her new self. Jill, like all of us, I think, experienced many voices inside her head. The extreme of this, some of you may know, is multiple personality disorder, but in a sense maybe we all have sub-clinical MPD. By giving voice to both her new deaf self and her old hearing self. Jill was able to let go—by realizing she could never let go. She realized an essential paradox of life: We cannot change until we accept who we are. On the one hand this makes no sense. That's why it is called a paradox. But on the other hand, one definition of wisdom is the ability to hold paradox, to know that two opposite statements can be true at the same time.

On a personal note I want to say how lucky I feel to know where you are but not yet who you will be. (Again please clarify this Mike. CP) I have learned so much. I think most of us are probably more comfortable hanging on to our piece of candy rather than taking a journey and letting go. But in Jill's own words, hanging on was only "comfortable in retrospect, terrifying

of the moment." When I told Jill I was coming here to lecture you today, I asked her if there was anything she would like to say to you through me. She said she would think about it and get back to me. She sent me a letter with a quotation from Eleanor Roosevelt, which I think is a fit closing. "You gain strength, courage and confidence by every experience in which you really stop to look fear in the face. You are able to say to yourself, 'I lived through this horror. I can take the next thing that comes along. You must do the thing you think you cannot do.'"

Dr. Harvey provides training and consultation on deafness/hearing loss, vicarious trauma and mental health issues. In addition to a private practice in Framingham, Mass., he is an adjunct faculty at Boston University and a consultant faculty at Pennsylvania College of Optometry, School of Audiology, where he teaches on-line courses relating to the psychosocial aspects of hearing loss. Dr. Harvey writes a regular column, "What's On Your Mind?", in *Hearing Loss*, the journal for Self Help for the Hard-of-Hearing.

In addition to over 40 articles, his publications include *The Odyssey of Hearing Loss: Tales of Triumph*, *Psychotherapy with Deaf and Hard of Hearing Persons: A Systemic Model*, and a co-edited book entitled *Culturally Affirmative Psychotherapy with Deaf Persons*. His most recent book is *Listen with the Heart: Relationships and Hearing Loss*.

Dr. Harvey is Co-Director of a private, non-profit organization, *Dialogue Toward Change*, dedicated to providing research, training and consultation services to alleviate the potentially negative impact of witnessing oppression.

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