

The Wonderful Life of Judith Snow

Jay Klein

Arizona State University

Jack Pearpoint

Inclusion Press

### The Wonderful Life of Judith Snow

On May 31, 2015, the world suddenly lost Judith Snow. On June 6, more than 400 people gathered in Toronto to remember, to share, and to celebrate Judith's life. Untold numbers of others joined the gathering in spirit through posts on Facebook and in various other forums.

Following the memorial service, our group of about fifty people continued telling and listening to stories long into the night. As we shared, we realized what we already knew: Judith Snow lived and touched thousands of lives. She was a person we thought we knew, but the complexity of who Judith was and how she changed the world was becoming clearer.

We were invited to help introduce, celebrate, and honor Judith Snow with thousands of people around the world. Finding a way to do this was a cherished but daunting task that required a massive community effort.

In the movie, "It's a Wonderful Life" George Bailey leads a somewhat typical life - a life any one of us could have led. As he contemplates death, however, George has the unique opportunity to look back and see how many lives would have been different if he had never lived. *"Strange, isn't it? Each person's life touches so many other lives. When they aren't around they leave an awful hole, don't they?"*

In the wake of Judith's death, we have been intensely immersed in stories about her and absorbed in our own personal memories. As we shared, we began to wonder, "What would our world be like if there had never been a Judith Snow?" We were amazed, once again, as we began to explore the overlapping layers of Judith's impact on our world and our lives. We had no idea, no way to measure her connections; we needed the help of a much greater community. So we posed this question to a group of people who knew Judith well: "How did Judith Snow affect YOUR life?" The list that follows is a compilation of our own thoughts and ideas along with

those of many others who contributed. You may think of additional ways Judith impacted your life and work. We invite you to post them to Judith's Facebook page at

<http://www.facebook.com/judith.snow.37>

### **Circle of Friends**

If Judith had not lived, and had not ended up in a nursing home, there would have been *no Joshua Committee – no Circle of Friends* (in its current incarnation). That crisis caused us to gather around Judith and begin to break down the walls of exclusion. Of course, there are now Circles of Friends and Circles of Support all over the world. Some may have a similarity or distant connection to that original Circle. Most will have evolved and been created as the 'circle virus' became an epidemic in response to the stresses facing families, the loneliness of exclusion, and networks and organizations genuinely searching for ways to support people and families to live full lives. We have no way to measure the impact and scope of connection to Judith, except that the core concept of Circles has touched hundreds of thousands of people around the globe, starting with the original Joshua Committee.

We are aware that if Judith had not done so, someone else would likely have conceptualized something like Circles. It is, in fact, an ancient concept. However, it was time to begin reviving mutuality and interdependence in our societies and it was Judith who was the spark, the catalyst, and thus, the connector for so many of us.

### **Asking the Great Questions**

Judith once said, "A great question refuses to be answered; so it keeps leading us into deeper connections with each other and into deeper thinking." Since Judith's life depended on the asking of great questions, she became a master of questioning. In so doing she made it possible for others to pursue great questions, taking them to places they did not even know

existed. As a philosopher, as a scientist, as a researcher, as an engineer, as a guru, and ultimately as an artist, Judith learned and in turn taught us to pursue the question of “how do I make the invisible, visible?” The implicit and explicit questions she stewarded led engineers to discover how a woman with only movement in one thumb could control a 300 lb. motorized wheelchair; and when her thumb no longer worked, how her breath could; how burly bouncers in upstairs nightclubs could make a building accessible; how adventurers could make canoeing and rock climbing possible; and how artists, engineers, and programmers could make it possible for her to paint and sculpt. But mostly, Judith’s mastery of the great question magnetically drew people to join in the quest; all were welcomed and ultimately the community that emerged would seek a bigger question, calling us all to go deeper.

### **Asset Based Community Development and More...**

Although Judith was deeply engaged in issues around disability, her interests and commitments were so much broader. Judith fulfilled a dream that she had for many years: to be rooted in her local community, with all the diversity, joys, challenges, and problems that are integral to all communities. As a neighbor and active leader in community development projects with her friends and neighbors, and in the local community health center (LAMP) as an executive member of the Board, Judith was a great neighbor and a respected agent for change by those who knew her in the Lakeshore community.

Judith was a founding member of the Marsha Forest Centre, and while the Centre supported Judith, she supported families and the development of Circles with the Centre for 25 years. She joined the faculty of the ABCD Institute with John McKnight, and was a key thinker and provocateur with that remarkable team of 52. She took community development into politics and challenged the nature of our democracy by being a member of the communist party, running

as a candidate in three Canadian elections. She was a live exhibit at the Royal Ontario Museum for an extended showing of nine months. It was an art exhibit, with Judith as a living part of the exhibit, shocking unsuspecting patrons and staff into a deeper understanding of possibility. She was key to a team of gamers who are still working on a computerized “Zombie” game where, in order to survive, you must help the Zombies to be included: a game of inclusion, now that is a Judith twist.

### **Respectful Interdependence**

The first time one met Judith they might have been struck with the thought that she was the epitome of independent living. Those of us who were fortunate enough to come to know Judith more intimately quickly learned that her life was lived in respectful interdependence. Judith depended on friends and allies to help her carry her message, which became our message.

Early on, Judith showed people what an independent minded woman who used a wheelchair could do. Later on in her career and life, Judith showed us what respectful interdependence could look like in so many different ways. As Judith spoke about the idea of gifts and giftedness, she was calling forward the idea of interdependence rather than independence.

### **Gifts**

Judith believed, and continued relentlessly throughout her life to tell us, that disability does not exist. She persistently reminded us that all people are always contributing something. Judith was uncompromising in pointing out that as we tell our stories, again between the lines, we are revealing our gifts, our capacities, and our strengths and if we learn to listen for gifts, we discover them. They were, of course, there all along, but all too often our scan for deficiencies and fixes rather than listening for gifts blinded us. Judith was positively loud in her conviction

that *everyone has gifts – no exceptions*. She gave us numerous examples in her many talks and in a short piece she wrote in 2011 entitled, “Notes on Gifts and Assets That People who are Vulnerable to Rejection Commonly Bring to Community.” In these notes, Judith pointed out that the people (she referred to in the title) offered marketable and highly desirable gifts such as hospitality (making people feel happy and listened to); grounding (slowing people down); skill building (causing people to try things they have never tried before while improving education and technology); networking (bringing people together who would otherwise never meet and asking questions others did not); economic improvement (providing jobs for people and providing a home for others), and emotional/spiritual healing (modeling forgiveness and allowing people to do something that made a difference).

It is our struggle to develop our willingness and sensitivity to hear and acknowledge these gifts. If there had been no Judith, so many gifts would still be unopened, un-given, undiscovered. While there are millions of gifted people who are yet to be revealed, we are all richer for those who blossomed as their gifts were unfurled. Judith had a part in acknowledging those bouquets of gifts.

## **MAPS**

Struggles for civil rights, for normalization, for integrated education and more were battlegrounds in this era. Judith was part of those struggles. With Marsha Forest and others, their focus was on *all* children being welcomed into regular classrooms in regular schools so that children would grow up together, learn together, and become citizens together. It was a simple idea, but implementation was a power struggle and a values challenge. In part because of the endless telling of Judith’s story, we were reminded that people’s stories have enormous power and leverage. The MAPS process was prototyped to counterbalance the devastating impact of

introducing a child into a classroom as a frighteningly medical ‘client’, by simply telling their story as a child and a fellow human being. To make it more transparent, a template of conversations evolved called MAPS. This allowed a child and ultimately a person of *any* age to explore their dreams and gifts by telling their own story.

Imagine how many of us have been liberated to discover our dreams, our gifts, and our capacities through processes like MAPS (and later PATH). Many other person-centered approaches with different names followed and continued to inspire and inform us. Imagine if Judith had not been part of those explorations. Where would we be today? Some things would have evolved because it was time, but Judith was a pioneer in shaping those conversations. The original conversations are long forgotten by most people who now benefit from these planning approaches, but if there had been no Judith (no George Bailey), where would we all be today?

### **Listening**

Judith discovered that people who do not speak are powerful communicators with a lot to say if we listen. Of course she was not alone in this discovery. But because she was Judith, her learning was shared widely and often reluctantly given credence because Judith said so. Then we would actually slow down to listen with more than our ears, to hear in our hearts the messages that individuals were communicating. Learning to listen is important and humbling at the same time because we are reminded of how closed we have been to so many messages that have been sent. Judith got on our collective and individual cases while hammering at us gently (or not so gently) to *listen*. Thus, although listening is as old as humanity, Judith played a huge role in reminding us of our responsibility as humans, and in teaching us how to listen. Without Judith, our personal capacity to listen would be diminished, and the injustice experienced by those not

being heard would continue. Judith was not the only coach for better listening, but she was at her best as a formidable force to improve our hearing.

### **Judith's School for Personal Assistants and Living Fully**

Over the years, Judith had approximately 600 personal care assistants who were in fact recipients of one of the world's most remarkable, entirely personal mentoring programs. Judith trained these 600 workers to manage her personal and career needs and to travel with her throughout the world. This experience helped Judith forge ideas about the essence of person-centered support and, in turn, offered her assistants a master class on how to live and participate fully in life.

Her assistants came from a variety of cultural, social, and economic backgrounds and they would go on to become artists, academics, entrepreneurs, social workers and much, much more – carrying with them Judith's lesson to listen to your dreams.

Judith supported this by listening to the inner workings of each assistant and tailored her instruction and their work assignments to help each of them to become the most remarkable person he or she could be. No one who worked for Judith escaped her grasp. All 600 of them were transformed. Some of them say that being Judith's personal assistant saved their lives.

### **Dreaming**

Judith's now famous story about wanting to be a truck driver (even though she had no physical control of her arms or legs) has allowed many of us to learn to listen between the lines for deeper meaning. Her courage to finally reveal her own outrageous dream and then unpack it so we could understand qualifies her as a great teacher. She convinced us of the obvious: that our dreams contain the seeds of the directions for our lives. The trick is that we have to listen for them and be willing to hear differently. Because so many of us have come to understand what is



under Judith's truck driver metaphor, the dreams of so many other individuals and families have been heard and honored. Bigger lives have been lived and expanded upon, all because of a dream.

### **Laser Eagles Art Guild**

Early in life, Judith painted in art therapy. She loved it but was told it was not art! The artist in her was sealed shut for decades, until she rediscovered it when she encountered and then reinvented painting with a “tracker” – a person who holds the brush for you but implements your artistic vision on canvas. For Judith, it was liberating, but because it was Judith, it also became a movement that now allows thousands who have mobility and communication struggles to reveal their own creative abilities and expression. It was a simple idea: artists using lasers to guide trackers to create art. Laser Eagles and its derivatives were born. In her unstoppable fashion, Judith was collaborating with a team of engineers and artists to invent new technologies to allow more people with mobility and community struggles to be artists through the use of iPads and beyond. Still in the refinement stages, these will be incredible legacies of creating a process where folks with few choices are genuinely in control of expressing themselves through art. Yet another group of people are connected to Judith.

### **Limits? What's That?**

Perhaps some of the most outrageous and inspirational undertakings were born of someone saying, “you can't” to Judith. She traveled the world, ate and drank with the best, hot tubbed and swam everywhere, canoed many times, and climbed the rock wall on a cruise ship because it was there. When she was told, “you can't do that”, she made a point of doing it. She became an actor, starring in two plays and several documentaries about her life. The last two were performed at the Toronto Fringe Festival and beyond. How many people have a play about

them called: “The Book of Judith”? Equally over the top, following her truck driver dream, she sold her home and invested in a car trailer (Avalanche), which she transformed into her portable bedroom. She took it on the road for months, on an inclusion and peace tour. It was, of course, impossible until she did it. Judith’s outrageous impossibilities inspired so many of us to push the limits, to say yes and to try a new challenge.

### **Individualized Funding**

One of the Joshua Committee’s goals was to find funding for Judith to live *independently*. Nursing and group homes were not options. Judith made it clear she would rather die. By any means necessary, Judith went about securing funding, and although the government of the day dictated that this was not a precedent, inevitably it became one. Little by little, one by one, others were able to crack open the door of options until there are now many choices – still not enough – but many. If Judith had not been dying to create that wedge, many more hundreds of thousands of individuals and families would have had to wait more years until another ‘system breaker’ created an opening, a crack in the dike of the system. Once again, untold numbers of people would have been stalled in their life journeys if not for Judith’s brilliant and courageous leadership.

### **Independent Funding Coalition of Ontario (IFCO), Homes, and More**

As the first person to have Independent Funding in Canada, Judith sustained her commitment for decades to extending it to all people through her deep engagement with IFCO. Housing has always been an issue for people with complex needs, and Judith was a primary instigator in the creation of several co-op housing projects that included access to extra assistance using the people and organizations hired by the individuals. This commitment carried into years of collaboration with the National Home of Your Own Alliance. For many years,

Judith was engaged with the National Institute on Mental Retardation (NIRM), TASH, and numerous other organizations, serving on their boards as a consultant, and as a major visionary to many. Judith was a relentless advocate for inclusion and one of the forces that created the Community Gatherings at TASH. If there had been no Judith, how would the missions and visions of so many of our organizations be different?

### **Trainer – Teacher**

Judith was a teacher. She taught and lectured at many universities. She was a founding member of the Toronto Summer Institute (formerly the McGill Summer Institute). She taught at Summer Institutes in Montreal, Toronto, Texas, Oregon, England and Ireland. She lectured at McGill University, York University, University of New Hampshire, Colorado State University, and Arizona State University. She was a teacher with Landmark, and a member of the Wisdom Circles. She mentored students, most recently a Computer Science Ph.D. student who lived in her home during an internship, which resulted in the development of a game engine; and a Ph.D. student in Public Administration and Policy who wrote a journal article on Judith's theory of inclusion. The list goes on. In the last months of her life, she was diving into a project that envisioned housing for all people in Africa. Judith never thought small.

### **A Good Friend**

Some people are simply compelling. They cause people to really hear, listen, learn, and grow. Judith was one of those people. A hundred of us could say the same words, but when Judith spoke them, people could truly hear what was being said. Judith shared her perspective in a way that people could relate to; they could understand. Reaching people in this way is a rare gift; Judith shared it graciously. She was an icon, a genius, a woman who moved mountains and changed attitudes every day of her life. In addition to all the pioneering, all the inspiring, and

numerous aspects of her life, there was also the ordinary Judith, the Judith who was a good friend. Those of us who knew her as a friend will struggle with the hole left in our lives from Judith's passing. We will keep and cherish stories, memories of times together, and moments when Judith made a personal difference in our lives through the sweet simplicity and complexity of friendship.

And on it goes. Judith was a pioneer on so many fronts. She was alive every minute of every day. She reached so far beyond disability. She was a person fully engaged in her humanity and human rights for all.

When Judith was 6, she had a conversation with her father about the fact that most societies would have killed her because of her disability. Judith asked, "why did you keep me alive?" Her father's response: "Perhaps you will discover the answer." We are the answer. Her life has reset the stage for so many of us, in so many ways. Thanks for being so alive, Judith.

Ironically, Judith often felt unacknowledged. Perhaps, like many artists, her life and work will be better acknowledged now that she is gone. The obvious way to honor her is to carry on with her work; keep fighting the good fight; teach, learn, listen, share, and build community at every opportunity; and keep Judith's spirit alive by telling her story, lest we forget what one person proved is possible during one life lived. One thing we know for certain: *it was a wonderful life.*

We are grateful for the honor of sharing the ideas, stories, history, and memories of Judith's life and impact. As Judith would have wanted, a small community of people contributed to this article. There were writers, editors, and reviewers, all struggling to honor Judith with mere words. The first group that helped create the initial draft included: Kim Klein, David Hasbury, Patti Scott, Joe Wykowski, and Lynda Kahn. The final review team included: Christopher Lee,

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