

A Path of Transformation



By Kathy Baroody

Transformation, you say? But the theme for this month is Caring for and Working with People with Disabilities. What does that have to do with transformation? Everything, believe it or not.

Let me explain.

For the past 31 years, I have shared my life with people whose way of processing the world around them differs markedly from the way many of us process reality. Their analytic and rational skills have developed differently than those of the majority of people. The people I share my life with aren't the ones I met at university or in the "professional" world. They're not the ones whose books I read or whose philosophical ideas I studied. The people I share my life with are the ones who have revealed to me what it means to be authentically human. These people – my friends – are often categorized as people with intellectual (mental) disabilities. They have touched me profoundly and, yes, they have transformed me.

All those years ago, when I was first introduced to the world of people

with intellectual disabilities, I was both afraid and determined to help. Afraid because I had had very little experience with people with any kind of disability and wasn't sure whether I would be able to communicate with them or even know how to simply be with them; determined to help because I felt sorry for them and figured that I was in a position (strong, educated, with access to resources, etc.) to help these "poor ones." What I discovered, though, in spite of my fear and my determination, was that I was somehow the "poor one" and that I was being invited into friendship, into relationships of mutuality with people who were often considered to be incapable of relationships. Each (disabled) person I met seemed to be asking the same question: Will you be my friend?

I was confused. Wait a minute! I was there to help them; I was there to teach them skills; I was there to show them how to behave "correctly." And yet, there they were, not necessarily rejecting my offer to help, but letting me know that *they* were also there to help me. I had entered their lives filled with a spirit of generosity (certainly not a bad thing, in itself) and a desire to help (also not bad, though it is often a one-way affair – the strong one comes to help the weak), and I discovered that these "weak ones" somehow pierced through my veneer of strength to reveal my own vulnerability. It wasn't something that happened overnight. No, it happened slowly, gradually, as the ordinary tasks and events of day-to-day life formed us into a community of friends. Slowly I came to realize that the diversity among us paled in comparison to what we had in common, to what brought us together. Each of us has a vulnerable heart, each of us simply wants to be recognized as a person of value, as someone capable of entering into meaningful friendships, as a person who



*Ayat and Amira know that playing together is one of the best ways to nourish friendship.
Photo by Elodie Perriot.*

is unique and whose presence adds richness to the lives of others.

The past few decades have seen tremendous progress with respect to the protection of human rights in general and specifically the rights of people with disabilities. The groundbreaking Universal Declaration of Human Rights that was proclaimed by the UN General Assembly in December 1948, detailed for the first time ever the basic human rights that must be protected for every human being. Its comprehensiveness is astounding, really, and constitutes a milestone for humanity.* And, of course, the Convention on the Rights of Persons

excellent initiatives and necessary. And the push towards greater autonomy and independence for people with disabilities – excellent and necessary as well. The focus on individual rights and independence plays a vital role in protecting persons with disabilities from abuse and injustice, and can lead to significant positive changes in society. There is no question that we need to continue along this path.

And yet, is this enough?

Perhaps one of the most basic of human rights – one that is not explicitly articulated in any official document – is



Rania and Sana sharing stories and secrets. Photo by Elodie Perriot.

with Disabilities that was adopted in 2006 at the United Nations Headquarters in New York, signals a huge shift in the way societies view people with disabilities: the person with a disability is the key decision-maker with respect to life choices.**

The world in general is much more aware of the history of injustice towards and even abuse of people with disabilities, and much is being done to rectify this: improvement in service provision, the availability of professional resources, training and formation programs for people working with this population – all

the right to friendship, the right to enter into relationships of mutuality where each person's unique gifts are revealed and shared with others.

A friend of mine, I'll call him Khaled (not his real name), had lived most of his life in an institution for people with disabilities. In addition to his mental disability, he wasn't able to walk, he needed help to eat and to do the tasks of everyday life that most of us take for granted. His health had deteriorated over a period of a few years, and one day he became seriously ill and was taken to hospital. A small group of his friends arranged our lives and work routines so

that at least one of us could be with Khaled at the hospital, 24 hours a day. Khaled was in a room with five other patients. All of them seriously ill. At first, the other patients and visitors, and even the hospital staff looked at Khaled with pity, seeing not only that he was ill but also that he had lived the entire 55 years of his life with severe intellectual and physical disabilities. For them, Khaled was a sad "case." What they weren't able to see at first was Khaled's gift for creating a community of friends around him. Khaled's interaction with his friends who came to visit revealed his joyful disposition and extraordinary capacity for friendship. Within a very short time, Khaled had entered the hearts of everyone in his room and they had all become an integral part of his world as he asked about and was genuinely interested in their families and their work and their hobbies.

One of Khaled's friends plays the 'oud. Khaled asked him to bring it to the hospital when he came to visit. Through Khaled's bold initiative and his friend's cooperation, the hospital room was transformed into a warm and welcoming "family" space, as everyone there joined in listening to or singing the traditional Palestinian songs that are so familiar to all. This "sad case" had been the catalyst for creating genuine joy in a space that is usually reserved for hushed murmuring and pity. As long as Khaled was a patient in that room, the atmosphere radiated warmth, hospitality, and hope.

What makes us human? Is it our intellect? Is it our physical or mental capacity? Is it our ability to "live alone" and do whatever we want? Or is it something altogether different, at the level of the heart? My friends have opened my eyes to a new way of understanding what it means to be human: our capacity to love and be loved, to relate to each other as friends, to welcome our interdependence, to accept our limits and to encourage each other to discover and develop our gifts. Ultimately, our humanity is rooted in our ability to reveal the truth to the other: You are precious, you are of infinite value, you bring joy to our lives.

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* <http://www.un.org/en/universal-declaration-human-rights/>

** <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>



Together on the journey of friendship: Haytham and Yousef. Photo by Elodie Perriot.



"Don't stir too much!" Amal and Sana show their culinary expertise. Photo courtesy of Ma'an lil-Hayat/L'Arche Bethlehem.