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It's PEOPLE with Disabilities

Focus on human being, be honest, natural, then an encounter can be beneficial to both individuals

stories by news editor LEE IMADA

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For those unacquainted with people with disabilities, a chance meeting can feel awkward and uncomfortable.

Take a deep breath and act natural, suggests Coleman Lyles, North American president of the Camphill Association, an international movement that operates communities for children and adults with developmental disabilities.

"I think that the rule of thumb . . . is to try to be honest and to be yourself," Lyles said last week. "Don't try to make a special effort because developmentally disabled people are sensitive.

"Try to take a deep breath and just say, 'I must remain natural and who I am.' "

Many people bring a desire to do right and to be cordial to people with disabilities but find themselves unable to communicate and interact with them. It's OK to feel "vulnerable," he said.

"I think we have to learn to embrace that discomfort, understand that it's normal but also understand that it can change," Lyles said, adding that some people have a greater natural capacity to relate to others, including to those with disabilities. "At the same time, you have to sort of accept it as who we are, who you are."

But for those who can break through the apprehension, there can be an inspiring connection that is mutually beneficial.

"People with developmental disabilities, they long to be met," Lyles said. "They want to be met, and the more you can meet them as individuals the happier they are.

"And you also will get something from that. That's another thing people need to experience. There is a mutual benefit from making the effort to meet such a person."

Lyles stopped by The Maui News on Presidents Day prior to a public meeting organized by the nonprofit Lokelani 'Ohana, which is endeavoring to create a Camphill-inspired community on Maui.

As North American president of Camphill, Lyles guides 12 Camphill communities and initiatives in the United States and Canada. He began as a house parent and financial director for Camphill Beaver Run, a community for people who are developmentally disabled, ages of 5 and 21, in Glenmore, Pa.

Lyles later moved west, helping to establish a Camphill community in Soquel, Calif. With Lyles as executive director, the residential care community for adults recently celebrated its 10-year anniversary.

Since its founding in 1939 by Austrian pediatrician and educator Dr. Karl Koenig, Camphill has provided residential care, education, training and vocational opportunities to thousands of people with developmental disabilities who live and work in extended-family settings.

"What is a Camphill community like? . . . First of all, you could call it an intentional community," said Lyles. "It's a group of people who have the intention to form a community together. And they are doing this with and for individuals with developmental disabilities."

Each community stands on its own and has unique qualities bound together by the model created by Koenig, who drew on the work of Rudolph Steiner, an Austrian philosopher and educator. There are 300 member communities and 30 member ones. Camphill communities run independently and can be found around the world. Some communities receive government subsidies; others survive on fundraising and family contributions, he said.

"The one feature that really distinguishes Camphill from other organizations is that the so-called staff . . . are committed Camphill co-workers, who live and work together with the people," said Lyles.

Camphill communities usually are found in rural areas, and have craft programs, farms and cultural centers with drama, art and music, he said.

"Art is a big of the piece of the Camphill culture — the whole idea of art for its own sake, and art as a vehicle for educating and training people, and also the concept of social art: that actually learning to live together is an art," he said.



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The classical arts, painting, music and drama, "help people to evolve and develop," he continued. The experience can be "a journey of self-discovery" for both the people with disabilities and the others, Lyles said.

Artistic training has a practical side, as well, by teaching problem solving, he said.

"It sounds ironic because most people think of art as gravy . . . as icing on the cake." Lyles said. "Nobody ever thinks that . . . a person who has artistic training becomes a more practical person in life and can think about things in a completely creative and out-of-the-box way."

Many who experience Camphill leave inspired.

"I think the thing they are inspired by is the experience that these places are . . . deep pools of human culture," he said.

There are Camphill communities that abide by the specific methodologies of Koenig and Steiner, and there are "Camphill-inspired communities" that do things differently but create those pools of human culture, he said.

Lokelani 'Ohana, which is working to form an "inspired community" on Maui, will take take root in the unique natural setting and culture of Hawaii as compared to the original Camphill community built by Austrian refugees fleeing Nazism in Europe.

"An effort in Hawaii started by a group of people . . . it's going to be completely different," said Lyles. "And should be. There should be no attempt here to create European culture."

When Camphill was born, people with disabilities were institutionalized. Since then, the world has come to the Camphill model with people with disabilities leaving institutions and being mainstreamed into the community. New laws have been passed mandating public education for children with disabilities. The Americans with Disabilities Act prohibits discrimination due to disabilities.

The laws are in place and the attitudes have evolved, but today the rights of people with disabilities face the squeeze of economics. With tight budgets, programs and services for people with disabilities are put in jeopardy.

"The people have these rights; that's absolutely clear. . . . One has to safeguard them because they are always under threat," said Lyles. "And the reason they are under threat has to do with money."

Not everyone has kept up with the times, Lyles added. He still meets people who are 30 years behind the times, thinking of "retarded" people living in institutions. These people choose to focus on the disabilities and not the person; this is why advocates prefer the phrase "people with disabilities" versus "disabled people."

It really comes down to changing perceptions and how one looks at people with disabilities.

"One of the essentials of Camphill is to really understand that when you are confronted with any human being, developmentally disabled or not, that is a spiritual being," said Lyles. "There is a spirit in that person . . . that in some respects, that spirit is whole and intact."

Lyles used the analogy of a pianist playing a piano that's missing a pedal or that's out of tune. That affects the music played.

"And in some respects if you meet a person with developmental disabilities, you can apply this," he said. "In their higher being, they could be a genius, but in this incarnation they're working with an instrument . . . that in some ways is disabled, developmentally delayed. And that has an effect on what they can do, how they can incarnate, how they can be effective in life."

Another perspective is that everyone has a disability, but it's a matter of degrees.

"Your particular disability might be very subtle," said Lyles. "You begin to differentiate less and less between the so-called 'disabled' person and the so-called 'normal' person."

Lyles referred to a lecture by Judith Snow, an author with cerebral palsy who depends heavily on others to take care of herself. "Poor Judith," many people say, but she contends that that's a matter of perspective.

Snow said she doesn't identify with her body the way most people "overidentify" with their bodies.

"I feel so sorry for you because you think you have to do everything for yourselves. You are the ones who are disadvantaged.'" Lyles said she told the audience.

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