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**Abstract**

This article contains the keynote address at a TASH conference in America by Frankie Lewis, who has helped many children leave nursing homes and enter regular homes. Her work epitomises the kinds of natural supports that make full inclusion possible. Her address provides a clear and fundamental explanation of citizen advocacy and her work in this area. **Keyword: Advocacy**

# Citizen Advocacy: Making A Difference In People's Lives

by Frankie Lewis

*At our 17th Annual Conference held in December in Chicago, the theme "Action for Inclusion" was exemplified by Keynote speaker **Frankie Lewis** from Macon, Georgia, who has helped so many children - to leave nursing homes and enter regular homes, to leave segregated centres in order to enter typical schools and to develop friendships with others. Her work epitomises the kind of natural supports that make full inclusion possible. The following is adapted from her Keynote address on December 7th.*

It is indeed a pleasure, as well as an honour, to come before you this afternoon and share my citizen advocacy thoughts with you. In order for me to familiarise you with exactly what citizen advocacy is and what I do, I would like to tell you the history of how we got started in Georgia and then I will proceed from there.

In 1978 in New York City, a nurse who was employed at Willowbrook Institution could no longer deal with what was happening to the residents who were living there. She tried to make differences through the administration, however her concerns went unheeded. Somehow she got in touch with **Geraldo Rivera** - I'm sure you're all familiar with him - who somehow got into the institution and did a documentary. The documentary was so devastating as to what was happening to the residents, that there were several Senate committee hearings held. The federal government, as a result of those committee hearings, said that each state had to have in place protection and advocacy for people with disabilities.

The governor got in touch with **Patricia Powell**, who is the Executive Director of our umbrella agency in Georgia. At that time she was working for another agency, so he asked her to funnel those federal dollars through where she was working. However, Patricia, and another colleague that was working with her, felt that it was too important to be funnelled through another agency so they decided to travel around the United States and see what other people were doing with those dollars. They ended up in Lincoln, Nebraska with **Wolf Wolfensberger**, who more than ten years prior to '78 had started what we call citizen advocacy. That is, where we ask ordinary citizens like yourself to enter into a voluntary relationship one-to-one with a person who is disabled, speak out on their behalf, make sure that they do not fall between the cracks in the system. In other words, represent their interests as if it were their own. Ms. Powell decided that this was what we wanted to do in Georgia. She returned to Georgia, lobbied the legislators and as a result, citizen advocacy is an arm of the federally mandated protection and advocacy for people with developmental disabilities in Georgia.

This brings me to what I do. In making Georgia a part of citizen advocacy, I recruit people from the community to enter into these voluntary relationships. The uniqueness of this is that the relationships are one-to-one. We ask the person to open their world up to the person with the disability - their relationship is independent of our office. In other words, it's a relationship that you would make with another person. We ask that person to put themselves in the place of the person with the disability. "What would you want for yourself if you were disabled? If you were in that person's position, what would you want?" And proceed to make it happen for that person. Now I would like to go further and say, in dealing with people with developmental disabilities - or people who are on the fringes of society in general - no matter how hard I try to understand or rationalise the reason for people being disempowered, those who are disabled,

homeless, or elderly, I cannot come up with a good reason why this has happened, is happening, and will continue to happen. Therefore those of us who are dedicated to the betterment of humanity must continue to take a firm stand on the side of justice.

As previously stated, you do not have to do citizen advocacy to do the right thing by people. However, no matter what role you have chosen or will choose in the future, the fact that humanity will be treated justly should be our main focus. If we selfishly put our material things of comfort above responding to the call of assistance to others, we will never acquire a just nature. In the 1990's, when we are so technically advantaged, so to speak, and ahead of our times in many, many areas, why do we still have people who are incarcerated in institutions - both private and public? Not because they have committed a crime against humanity, but because they are different in looks or behaviour, and this has happened from birth or from an accident or because of age. Our reaction to these differences have allowed people to be seen as menaces, depraved or a burden. To be seen as people who are undesirable to have as friends, neighbours or as a part of our families. Our indifferences have caused the establishment of large brick buildings with bars or heavy wires over the windows and doors that sends the message to the general public: the people who exist here are to be feared. We have created special programs that address individual needs by paid staff.

Now I'm not saying that paid services are not necessary in many instances, but what I am saying is that life for people on the fringes of society will be more bearable and life sustaining if there are people in their lives who stand beside them because they want to, not because they are paid to ... people who believe in and fight for freedom and justice for all, as the Preamble to our Constitution so ably states, which we learn as children and carry with us throughout our lives. In the late 1700's when slavery was just as prevalent in the North as it was in the South, what made a modest group such as the Quakers not only speak out against unfair bondage of people, but proceed to do something about it? What made men like **Benjamin Lay** stand up on the side of justice against his own people? What made people like **Anthony Benzaik** and **John**

**Woolman** so adamant about the abolition of slavery, and promote the welfare of those who were enslaved? And I'm sure you know, Benzaik took it upon himself to educate the slaves himself, and to his amazement, he learned that these people could learn and had many talents that were suppressed because of their oppression.

Does this sound familiar to you? But there was still separatism. There was separatism among the people. Does that sound familiar to you? There is no way that I can delve into the good works done by the Quakers to abolish slavery once they realised that the bondage of people was against their religious teaching, and morally wrong. In comparison, in the early 60's, as brought out in the history of citizen advocacy, the founder Wolf Wolfensberger initiated recapturing the idea of being a good neighbour, the idea of one person - who is seen as valuable - speaking out on behalf of another person, who is seen as devalued. The Association for Persons with Severe Handicaps is certainly taking a progressive look at what should happen if people who are handicapped are included in community.

Those of us in citizen advocacy are initiating relationships that get back to the old fashioned attitudes of neighbour helping neighbour, restoring dignity and self-respect and assisting people with having their desires become a reality through advocacy. There are many other worthy ways of responding. However, I don't have enough time to name those in the time allotted. With so many of us travelling down the same road of justice, why are there still overcrowded institutions? Why is there exploitation of the disempowered and the blatant disregard for the fact that all of life is precious, and as I have been told, we all have inalienable rights. We must make adjustments in our lives that promote inclusion of all people, unselfish giving and conscious love and justice for humankind.

There are approximately 2000 of us in this room. What if each one of us asked ten of our friends or acquaintances to individually respond to a disempowered person in a positive

manner, to focus on their capabilities rather than their inabilities or disabilities? There would be over 20,000 people all over the United States and Canada making a difference in people's lives. This is not a small number when you think of the people who will be influenced by such an unselfish display of love for their fellow man.

Finally, those of us who are parents, and I'm sure there are many of us in here, from the time our children are born we begin to teach them. Teaching them, among other things, those that are most familiar to you, "Mama" and "Dada". We repeat these words to them until they learn them. Let's add one other thing to their knowledge: it is right to be just and fair. Remember -please take this with you - we cower to injustice when we don't stand up.