

“Community Development Work With Disabled Children in Uzbekistan: The Beginnings Part 1”

Introduction:

My name is Kimberly Wood and I am currently working with Central Asian Free Exchange, C.A.F.E., a non-governmental organization, “NGO”, in Uzbekistan. The aim of C.A.F.E. is to do community development work focusing on community needs while incorporating appropriate culture into sustainable work in this area of the world. I am currently working with a new team under C.A.F.E. to establish an office in Navoiy, a city in Uzbekistan. I, specifically, am working under a two year contract to work with the local community to establish a rehabilitation clinic for disabled children. The primary purpose of this article is to educate occupational therapists on the needs in Uzbekistan. Another purpose stemming from this is to encourage therapist involvement with disabled children here in Uzbekistan in order to develop and support the network of available resources, particularly with those therapists who specialize in pediatric rehabilitation. Since this work is young in its development, I will describe the work process of our community development work in this article, “Part 1”, and then provide more details of the actual work with disabled children in a later article once this work becomes more established.

Work Beginnings:

Since C.A.F.E. desires to work with national partners, meeting significant needs, and do sustainable development work, our first step was to locate a local partner. In collaborating with one national, we discovered that her desire was unique compared to others in that she had a long standing dream to help disabled children by teaching parents how to help their children. As our interactions with her increased over the next few months, we discovered she had a well developed network of people in the community and surrounding regions (local heads of the city as well as parents). She had done research identifying the numbers of disabled children in each of the regions. Not only these things, but she was weekly involved with helping children by giving humanitarian clothing aid. Our next step in working with her was to meet those within her network and discover the kinds of childhood disabilities in our city.

Culture and Clinical Finds:

First, we were invited by the local mayor to explain our plans and obtain his permission and guidance for this work with disabled children. Second, we collaborated with local doctors and community leaders to visit local disabled children and their family's'. The community reported the most common disabilities to be encephalopathy, cerebral palsy, bone contractures (some related to cerebral palsy), speech deficits (limited to no speaking apparently not related to cognitive deficits), asphyxia, some visual and hearing deficits, and anemia. The current health system appears to include doctors and nurses. As far as available rehabilitation, most of the regions do not have access to any. The only possible “rehabilitation” seems to be in the main city. At this point in time I understand that there is some kind of “doctor” that does what is called “massage”, electrical treatment, and paraffin treatment. I have been unable to actually observe these foregoing treatment sessions. Vitamin (mostly C and B1, 6, 12) and glucose injections seem to be given a lot for anything from the flu to neurological deficits such as cerebral palsy. Whether it be the city or surrounding regions, people seem to want help for their disabled children. The popular view appears to keep the child at home rather than send them to an orphanage. However, it appears that these children are literally kept at home all day without attempts to involve them in any formal education or seek medical attention. My local partner, as well as a foreign therapist in another city, states that many disabled childrens parents fear community opinion. Furthermore, parents of non-disabled children fear their children will become disabled if they play or attend the same school with disabled children. Although there are many types of disabilities, some even with reported greater numbers, we have decided to pursue program development with cerebral palsy. Starting with cerebral palsy will enable myself, the only therapist not to mention medical worker currently on this project, to start “small” staying focused while addressing key therapeutic issues.



Resources:

Available rehabilitation resources in the country are minimal and most of the resources I have found are from other foreigners in two far away cities. I have further received therapeutic literature collaboration help from a few contacts with American occupational and physical therapists currently working in other countries. Therapists currently in America have also given some development suggestions. The World Federation for Occupational Therapy has further provided invaluable book resource contributions in addition to network assistance. Finally, friends from the States are in the process of sending learning development toys. Given this resource network and internet dialogue, I am able to begin establishing a clinic and writing training programs for parents.

Plans:

Currently I am in the process of supplying a remodeled building with therapy equipment and resources. Since the philosophy of our program is to teach nationals who will train others, I am looking for two to three local women who are interested in helping disabled children, desire to learn, and teach parents. The foregoing philosophy stems out of the desire to have a sustainable and reproducible program run by nationals.

Struggles:

Patience with my growing language skills and culture knowledge is an ongoing weakness for me to overcome. Fortunately, I have a few committed friends to help me in this area. It is also difficult having limited local resources for program development help, networking, as well as supplies. Finally, learning about the needs of the community when they do not have a concept of my skills and knowledge of their needs is complex especially as I desire to helping the community learn how to help themselves. Despite these personal weaknesses, difficulties, and complexities, I am grateful for this opportunity to help people with great needs as well as grow personally in skill and character. My life is certainly more enriched as a result of this endeavor!
(Please look for the upcoming "Part Two" article reporting the progress of this new work!)

Kimberly Wood, Occupational Therapist
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