



# Hope for Autism and Developmental Disabilities in the DPRK

BY **STEPHEN & JOY YOON**

**Stephen & Joy Yoon** graduated from Olivet Nazarene University with majors in Biology in 1999. Stephen went on to earn his doctorate in Chiropractic from Cleveland Chiropractic College in Los Angeles in 2004 and a Ph.D. in Rehabilitation Medicine in DPRK in 2012. Joy earned her masters degree in Biology/Ecology from UCLA in 2003 and a certification in Educational Therapy from UC Riverside in 2017. For the past eleven years, Stephen and Joy have been serving as Christian workers in North Korea. Their cross-cultural work in North Korea has included Christian business, humanitarian work, and medical outreach.



Treatment for children with developmental disabilities is available for the first time in the DPRK. Prior to this project, no official specialized medical training or therapy existed for children with cerebral palsy or autism in the DPRK. Both were considered untreatable or were treated with lack of expertise. Worldwide, according to the Center for Disease Control and Prevention, 3.3 out of every 1,000 children are affected by cerebral palsy and 1 out of every 110 children are affected by autism. Therefore, specialized treatment of pediatric developmental disabilities was a great need in the DPRK.

Now, through one American family, treatment for children with developmental disabilities has begun in the Kim Il-sung University Pyongyang Medical School Hospital. Although this family has been working and living in the

DPRK for over ten years, they moved to the capital city of Pyongyang in 2013. They became the first American family to send their children to the Pyongyang Korean School for Foreigners and to reside within the apartments of the Foreign Diplomatic Compound. There have been many firsts for this unique American family, but the greatest firsts have been in the strides made for the rights of children with disabilities within the DPRK.

With skills in rehabilitation medicine and special education, this family is implementing, for the first time in the DPRK, treatment and education for children with developmental disabilities in the medical university system. Initially, the local hospital administrator did not acknowledge that developmental disabilities, such as cerebral palsy and autism, existed in the nation. However, as patients came

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to be treated in the hospital, the need to treat pediatric developmental disabilities was officially recognized.

One of the first patients with cerebral palsy who brought awareness to disabilities throughout the nation came in the fall of 2013. She was ten years old at the time and diagnosed with spastic quadriplegia. This young girl could not walk, so her classroom teacher would strap her to her back and carry her to school every morning. Once at school, her teacher would then strap her to her chair so she could listen to class lectures. This girl's greatest dream was to walk to school one day with the rest of her classmates. Following the beginning of official treatment for children with cerebral palsy in 2013, she was finally able to receive medical care. After approximately 11 months of therapy, she realized her dream: she walked out of the hospital! The local broadcast network came and televised her discharge and today she is attending school with the rest of her classmates. She now has a new dream to become a rehabilitation doctor so that she, too, can help children like herself.

Thousands of children like her are waiting in the DPRK for medical treatment and many of them have never attended school. Through this family and the establishment of a therapy program for children with developmental disabilities, other children now have hope for the future.

After the hospital's successful treatment of children with cerebral palsy, the Department of Public Health began establishing pediatric rehabilitation centers in all 10 provincial children's hospitals. In addition, a cohort of doctors is being trained in treatment methodologies at Kim Il-sung University Pyongyang Medical School Hospital. The government has ensured the development of this specialty within all 10 medical schools in the country by signing an agreement with the sponsoring NGO known as IGNIS Community. Even the former leader, Kim Jong-il and the current leader, Kim Jong-un have signed off on this project!

But the story does not end there. Now, with the help of a partnering American therapist, the program for children with developmental disabilities has expanded to include not only children with cerebral palsy, but also children with autism spectrum disorder (ASD). Prior to June 2015, there was no diagnosis or therapy of any kind available for children with ASD in the DPRK. ASD was essentially unknown and both children with ASD and their parents struggled as they tried to cope with the challenges that faced them with neither resources nor skills.

In two short years, the Pyongyang Medical School Hospital has made great strides in learning about ASD and the therapies available. In cooperation with the DPRK government Ministries of Public Health, the hospital has hosted a series of four separate weeks of lectures and hands-on therapy skills training provided by IGNIS Community volunteers. Doctors who have participated in this training will be the pioneers of ASD therapy in the nation. In addition to specific skills and techniques in facilitating social interaction and communication in children with ASD, the training content also included foundational theories and philosophies of practice. Through the lecture content and discussions about different models of disability, whole child development and the importance of cultivating trusting relationships with children and families, attitudes and perspectives of both doctors and families have changed.

A seven-year-old boy with autism spectrum disorder (ASD) walked into the therapy room with his mom, his eyes wide and face ashen with fear. He had never spoken before and could not attend school because of his challenges with sensory processing and social communication. He could not tolerate anyone near him and responded by crying out in fear or spinning a toy to help relieve his anxiety. By the end of a 30-minute therapy session, he was engaged in a beautiful, back-and-forth tickle game with the therapist, laughing loudly and deeply. He excitedly grabbed the therapist's hands and placed them on his stomach and even spoke his first partial word to ask for more tickles! His mom, with tears in her eyes, said that this was the happiest she had ever seen her son.

Another mom of an eight-year-old boy with ASD openly shared her struggles of raising a child with special needs. Her despair turned to hope as the therapists listened to her, encouraged her, and reassured her that she is not alone.

These are just a few of the stories of hope and healing that have taken place in the lives of children and families who come to the new pediatric therapy clinic started by IGNIS Community at Kim Il-sung University Pyongyang Medical School Hospital.

Besides the lecture component, the ASD training series has also included a significant amount of hands-on training. Morning lectures about theory and techniques are then implemented in the therapy clinic in the afternoon. The techniques are first modeled by the visiting western therapist and then each therapist-in-training has had

the opportunity to practice the skills they have learned as they engage with a child with ASD and his caregiver. Each therapy session is followed by a time of debriefing and questions. The DPRK therapists and other observers have noted this debriefing time as one of the most helpful methods of learning for them, enabling them to see how techniques can be utilized and adapted to real-life situations based on the child's individual needs.

The doctors are eager to learn and are motivated to help children with the new skills they are acquiring. The hospital, now equipped with basic developmental milestone charts and ASD screening materials, is screening each child that comes through its doors for ASD and other developmental delays.

Pyongyang Medical School Hospital has seen this training series as valuable and has invited others to join their learning. As of June 2017, a total of over 30 doctors from Pyongyang Medical School Hospital, Pyongyang Children's Hospital and the DPRK Disability Federation have taken part in the lecture series. The Assistant Director and Chair of the Neurology Department at Munsoon Rehabilitation Center have also expressed interest in participating in future training.

The lecture series on ASD has not only been helpful for doctors and therapists providing direct care; but has also caught the increasing attention of government officials from The Ministry of Science and Technology and the Ministry of Public Health. Their increased awareness and education about ASD is crucial in the adaptation of the medical system and formation of policies to include the diagnosis and care for children with ASD and other developmental disabilities.

IGNIS Community envisions that through the training of medical students in rehabilitation specialties, through empowering parents and through igniting change in the society's perspective of disability, children with cerebral palsy, ASD, and other developmental disabilities will be transformed to their full potential and be able to participate in their community. Child by child, one family and one doctor at a time, we are seeing this vision become a reality.

