In the fall of 2014, I was on a team of rehab professionals traveling to Jamaica to provide specialized custom seating to the residents of the Mustard Seed Communities (MSC). I returned in the spring of 2015 for another trip with a focus on evaluations for an upcoming distribution. Although I’ve been on many mission wheelchair trips, Jamaica is a very special place and MSC is a unique partner.

MSC began in 1978 in an impoverished community on the outskirts of Kingston, Jamaica, as a home for a handful of abandoned and disabled children. Today they serve more than 500 children, young adults and families who belong to the most vulnerable groups in Jamaican society. The population of their homes includes children and young adults with disabilities, children affected by HIV/AIDs and teen mothers along with their babies. MSC Jamaica also manages a number of community outreach programs to combat poverty and provide education to local populations. Their vision for each apostolate, residential cottages on MSC properties around Jamaica, is to create a loving and caring environment to aid in the physical, mental and spiritual development of their residents.

A majority of their programs focus on the care of children with disabilities. The residents of their homes have a wide range of physical challenges requiring wheelchairs including children with cerebral palsy, hydrocephalus, spina bifida, and developmental disabilities along with many other orthopedic and neurologic diagnoses (see Picture 1).

Our team leader from Atlanta, Georgia, is Liz Merrick, who coordinates teams of RTSes, OTs and other volunteers to travel to Jamaica. Merrick had a brother with special needs, so she has worked with the disabled population and quickly developed a passion for the residents in Jamaica. Her history with MSC began 13 years ago when she embarked on her first mission trip with her local church. She returns two to three times annually with a variety of volunteers including high school and college students, therapists and RTSes who embark on a rich experience and develop special relationships with this unique Jamaican population.

Merrick soon discovered that Jamaica has limited resources due to their economic situation. She raised funds and in 2009 sent the first shipment of standard wheelchairs to Jamaica. MSC is the in-country partner—receiving, clearing customs and storing donated rehab equipment until the team of therapists and RTSes match and fit residents to their first wheelchairs.

Merrick saw many residents either confined to bed or sitting poorly in large, heavy, ill-fitting standard manual wheelchairs. The importance of good seating to improve the quality of life for these residents including positioning for safe feeding and attending activities while upright and in midline, was readily apparent (see Picture 2). She raised funds to buy custom manual wheelchairs and foam-in-place seating kits, as well as arranged shipping and needed experienced rehab professionals to complete seating fabrication to improve client support and address severe positioning needs. Due to the lack of medical and therapeutic intervention, many residents had fixed orthopedic limitations.

In 2013, Merrick coordinated with Wheels for Humanity to send a shipment of custom wheelchairs to Jamaica for the physically challenged residents in need of both seating and mobility. My first trip in 2014 focused on fabricating foam-in-place seating systems for the residents who were faced with extreme seating challenges. The ability to bring this technology to a developing country is a progressive way to meet those needs.

Our team met in Kingston where we were greeted by the friendly staff of MSC, including our driver and local
team leader for the entire trip around the beautiful Jamaican cities and countryside. In our 10-day trip we visited six apostolates with residents who needed manual wheelchairs and seating systems.

Once the team arrived in Kingston, we traveled to, and resided in, the dorms at Sophie’s Place, where the younger children from infants to primary school-age children reside (see Picture 3). It was to be our “home base” while seeing residents in the southern part of Jamaica. A mix of both ambulatory and non-ambulatory children reside there and others are bused to school.

The largest MSC apostolate is Jerusalem where multiple programs are offered and more than 150 teen and adults reside. On many visits I saw older residents helping the younger ones by feeding them, assisting them as they participate in activities and pushing them in their wheelchairs around the eight-acre community.

Local caregivers with a special interest in therapy were available in some locations and we partnered with them in gathering information during the evaluation. Many children had severe orthopedic asymmetries at a very young age secondary to relentless spasticity, although they had been positioned and received range of motion. As a result, these children needed to be accommodated in custom seating systems. Some of the initial wheelchairs provided had contoured and planar seating, including secondary supports, however the children were not well-supported (see Picture 4).

Surprisingly, all the residents we saw had excellent skin condition with no pressure ulcers or any discoloration. The caregivers took very good care of the children’s hygiene needs and repositioned them frequently. The humid climate results in supple skin.

Although many residents presented as potential candidates for foam-in-place seating and 12-14 kits were purchased, we only fabricated 10 foam-in-place seating systems. Some of the children who had active functional movements were kept in their original seating systems, as we did not want to sacrifice function for positioning by limiting movement (see Picture 5).

A young lady with cerebral palsy and extreme spasticity sat with pillows in a standard manual wheelchair. She had severe internal rotation of her hip, which resulted in her foot being outside the width of the wheelchair and being propped on pillows. The RTS mounted a lateral trunk support on the outside of the frame to support the foot. This increased the width of the wheelchair, however the staff found this manageable (see Pictures 6 and 7).

A resident in the apostolate Jerusalem, nicknamed the “Mayor,” arrived for his seating evaluation in a very recumbent position in his reclining wheelchair — the only wheelchair available at the time. However, once he received a tilt in space manual wheelchair with a custom seating system, he was able to sit more upright and with better support. His improved position provided better respiration and resulted in increased speech volume.

Most of the residents who were brought to the team due to concerns about the poor fit of the wheelchair were actually not properly positioned. The problem
was not an incorrect fit or the wrong type of wheelchair, but rather how the residents were placed into that wheelchair.

Resident’s hips were brought back fully on the seat, pelvic positioning belts properly adjusted to maintain the position of the hips and anterior trunk supports positioned properly at mid-chest to reduce risk of choking. With these changes, the residents looked better in their wheelchairs and the staff agreed. Many therapists and staff were trained using these techniques and provided with instructional handouts and a training video to reinforce best practice to keep residents healthy and as safe as possible.

Education and training is as important internationally as it is stateside. We had many opportunities to meet with therapists, caregivers, staff and administration regarding wheelchair safety and proper positioning. The training video created will be shared with other apostolates for both present staff as well as incorporating this information in basic training for new staff. The RTS provided training on maintenance and repairs and donated tools as well as, extra hardware, cushions and other items such as anterior trunk supports and pelvic positioning belts for ongoing and future adjustments and modifications.

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REFERENCES:
1. MUSTARD SEED ALSO HAS COMMUNITY PROGRAMS IN NICARAGUA, DOMINICAN REPUBLIC AND ZIMBABWE.