The ROC Wheels Family Guide: A Caregiver Education Manual for Wheelchair Provision in Less-Resourced Countries

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Summary

The ROC Wheels Family Guide was created for the ROC (Reach Out and Care) Wheels organization; it is an educational manual for caregivers of children with complex seating and mobility needs. Information pertaining to seating and mobility was gathered from various resources in order to provide education to the caregivers regarding how access to wheelchair mobility can optimally benefit the overall health and quality of life of the children and the caregivers. These resources included peer-reviewed journal articles, experiential input from an industry-leading pediatric wheelchair designer and founder of a charitable wheelchair provision organization, seating and mobility resources available from the World Health Organization, and an electronic survey that gathered information from occupational therapists, physical therapists, and other seating and mobility professionals who have previously volunteered for international wheelchair distributions.

A Spanish edition of ROC Wheels Family Guide was distributed initially during an annual wheelchair distribution trip to Sonora, Mexico in March 2015, and the ROC Wheels organization now has the ability to modify and translate the ROC Wheels Family Guide as needed to serve similar populations in other countries.
The ROC Wheels Mission

To mobilize people with disabilities in developing countries and to foster partnerships through ministry, youth empowerment, wheelchair distributions, manufacturing opportunities, and educational development.

Literature Review

The implementation of better caregiver education means tailoring the information to successfully meet each individual’s needs. Client-centered care involves more than the quality of the education. It requires consideration of how each client learns best and also knowing the best ways to deliver the information. According to Beagley (2011), it is imperative to use simple language, and any complex words should be clearly explained. Proper education leads to empowerment; this accomplishes an essential aspect of the occupational therapy philosophy, which is client-centered care (Wingard, 2005). Empowering clients through education provides them with the tools they need to actively participate in treatment, cope with illness, improve quality of life, and seek the resources they need; this includes inspiring and educating the clients to see how information can positively affect their quality of lives (Alger et al., 2015).

Another essential aspect of the occupational therapy philosophy is the experience of a life change from one of “seclusion” to one of “inclusion” for the families who are recipients of a donated wheelchair (Khasnabis, 2008). In a qualitative study by Glumac, Pennington, Sweeney, and Leavitt (2009), researchers explored the experiences, perceptions, and needs of caregivers receiving wheelchairs donated for non-ambulatory children in a less-resourced country. Caregivers expressed a strong desire for more support regarding wheelchair use. The potential outcomes of proper seating and positioning include balance between stability and mobility in a seated position, prevention of deformities, safeguarding of tissue, decrease in fatigue, enhanced internal functions and level of comfort, and facilitation of participation in functional activities (Cook, Polgar, & Hussey, 2008). Wheelchair safety instructions educate the caregiver on safe ways to navigate terrain, curbs, and stairs in order to prevent injury from falls. Wheelchair maintenance includes inspecting wheels, axles, frame, nuts, bolts, and so on; keeping a regular maintenance routine reduces risks of potential injury from mechanical breakdown. Cleaning the wheelchair with a mild disinfectant can assist in infection prevention for the child and the caregiver (Gardner et al., 2014). Maintaining the four principles of proper body mechanics may prevent injuries to the caregiver and the child (Blair, 2008). Additionally, it is “universally recognized that an appropriate wheelchair is a precondition to enjoying equal opportunities” and “personal mobility is an essential requirement to participating in many areas of social life” (Khasnabis, 2008, p.22).
ROC Wheels Family Guide: Proper Positioning

When children do not sit upright, they have trouble with breathing, eating, talking, and moving the upper body. The goal of sitting upright using a wheelchair is to provide the child with enough trunk support so that energy can be used to participate in any given task of his or her choice. The child should not struggle to stay upright or be afraid of falling. Making sure the child has a proper sitting posture will promote overall health and prevent deformity (Paleg, 2006).

RESPIRATION: The lungs are compressed when a person slides forward and sits in a slouched position. Breathing and being able to cough can become difficult. The breathing risks for sitting in a slouched position are poor capacity of the lungs and lung infection. Also when a person sits slouched, the lungs do not expand fully.

DIGESTION: Sitting in a slouched position compresses the stomach. A compressed stomach and intestines can lead to severe constipation.

BLOOD CIRCULATION: Sitting in a slouched position combined with weak or inactive leg muscles decreases the blood flow in the legs. This increases the risk for swelling and ulcers (Engstrom, 2002).

ROC Wheels Family Guide: Pressure Relief

Wheelchair seating may lead to increased friction on the skin. The main areas to watch for redness or pressure ulcers are on the bony areas of the buttocks, legs, and elbows. If redness occurs on any area that does not fade away within 30 minutes, it may be the beginning signs of skin breakdown and potential pressure ulcers. However, the risk of pressure ulcers may be lessened with special attention. Special attention means making sure skin is clean and dry and inspected. Repositioning should occur every hour.

1. When a wheelchair does not properly fit a child, skin breakdown may occur on bony areas. Use the instructions for adjusting for growth included in this manual to help prevent friction.

2. If the wheelchair seat is too small, skin breakdown can occur on the bony parts of the buttocks area. Use the instructions for adjusting for growth included in this manual to help prevent friction.

3. Wheelchair cushions should be checked daily for cleanliness. Impaired bladder control or excessive sweating may contribute to skin breakdown. Keep the child’s clothing and seat cushion clean and dry. Make sure the cushion is fully dry before returning it to the chair.

4. If your child can push up from the wheelchair arm rests, remind him or her frequently to do a push up every 15 to 20 minutes to relieve pressure and allow blood to circulate to all areas. If the child needs help to change sitting positions, the caregiver should change the child’s sitting position at least once per hour (Samaniego, 2003; Stockton & Parker, 2002; Ding et al., 2008).

5. The tilt-in-space function of the ROC Wheelchair can assist with pressure relief. In order to effectively reduce pressure from the buttocks and thighs, the wheelchair should be tilted to 45 degrees a few times throughout the day.
In order to transport a person in a wheelchair, it is important to know how to handle a wheelchair safely and securely. It is also important for the caregiver to be familiar with the safe use of the wheelchair in order to protect the person in the wheelchair as well as the caregiver. DO NOT ATTEMPT to navigate a wheelchair unless you are ABSOLUTELY sure that you can handle the weight of the individual and maintain full control at all times. Before pushing the wheelchair, be SURE that all belts are fastened, arms and feet are secured, and arms are placed on the therapeutic tray.

**SEAT BELT:** ALWAYS fasten the seat belt. Make sure the seat belt is tight enough to secure the person for safety, but the seat belt should not bind. Make sure the seat belt is not overly tight each time by slipping two fingers between the seat belt and the child.

**BRAKES:** Lock the brakes on the wheelchair before transferring a child. Always engage the brakes when the child is unattended.

**NEVER tilt the wheelchair forward.** Always tilt it backward. The child may fall out or become injured by tilting the wheelchair forward when navigating curbs and other structures.

When a chair is being pushed on rough ground, gently tilt the chair onto the back wheels.

When going down a curb, turn the chair around in a backward direction. Once the caregiver is on the lower part of the curb, gently and slowly guide the large wheels off the curb. After the large wheels are on the lower part of the curb, tilt the chair back to allow room for the casters. Continue to move backward until casters can be rested on the lower part of the curb.

When going up a curb, tip the chair gently and place the front wheels on the sidewalk. Once the back wheels are touching the curb, ease the chair forward and roll the wheelchair gently onto the curb.

(Bolding, Adler, Tipton-Burton, Verran, and Lillie, 2013)
ROC Wheels Family Guide: Adjusting for Growth

English Version

Adjustable Parts

Head Support
The head support should provide enough support to ensure the child’s safety while preventing the child from shifting or engaging in functional activities.

Chest Harness
The harness should be firm enough to support the trunk and allow enough space to breathe properly. Never allow the chest harness to interfere with the seat belt.

Seat Belt
Always fasten the seat belt first. The seat belt should help secure the child in a stable position allowing maximum stability.

Abductor Block
The abductor block keeps the legs aligned with the pelvis.

Foot Bed
The foot bed should firmly support the feet and legs to ensure stability.

Therapeutic Tray
The therapeutic tray provides upper body support as well as a platform to rest for feeding, writing, and play.

Ankle Supports
Ankle supports provide traction and prevents the feet from slipping while allowing controlled movement.

Hip Guides
Hip guides facilitate high alignment, medial or lateral positions, and prevent hip abduction. They help with maintaining the pelvis on the seat cushion.

How to Make Adjustments

Tool Kit
- 7 x 7 x 7 in folded screwdriver
- Cross screwdriver
- Measuring tape

Seat Belt
Always secure the seat belt first. It should be at least 1.5 in lower than the shoulder blades. Depending on the child’s position, the seat belt position may have to be moved to keep the pelvis in the neutral position.

Adjustable Handle Bar
The handle bar is adjustable by changing the position of the handle. When you are adjusting the seat back, you can flip the handle bar outward for easier access and back inward for additional hold.

Spanish Version

Piezas Ajustables

Cinturón de seguridad
El cinturón de seguridad debe mantener la posición de la cadera y el tronco. Dependiendo de la posición del niño, el cinturón de seguridad puede necesitar ser ajustado.

Cojin de asiento
El cójín del asiento debe ser firme y adecuado para el niño. Debe permitir que el niño sienta el suelo con firmeza.

Adicionalmente Detalladas Instrucciones con Imágenes
ROC Wheels Family Guide:  
Wheelchair Maintenance Schedule

As Needed:

- Cleaning the cushion: It is best to clean the wheelchair cushions when it is time for the child to go to bed. This will allow ample time for the cushion to dry. The wheelchair cushions should be cleaned each time the cushions become soiled to decrease odor and potential for infection.

Weekly:

- Wipe the chair down with a damp cloth. Use mild detergent if needed to reduce germs.
- Check the wheel brakes and make sure they are easy to activate. Make sure they are secured tightly to the frame.
- Remove any hair, strings, or other objects from the wheel axles that make the wheel hard to turn. Clean off any sand or road grime that can wear down parts over time.
- Inspect the wheels to ensure the spokes from the axle to the rim are secure. Check to make sure the rims are not bent.
- Check the front casters for any wobbling or excessive motion.

Monthly:

- Check for loose nuts and bolts. If any nuts or bolts need to be replaced, use only the same size, grade, and strength of the original ones.
- Check for any cracks in the frame.
- Check the wheel alignment.
- Thoroughly clean the chair with a damp cloth.

Yearly:

- Lubricate any pivot points. Wheelchairs with reclining backs and tilt-in-space should return to the upright position without difficulty.

(Sekerak, 2003)
ROC Wheels Family Guide: Outcomes

WHO: 2 Belmont University OTD students, 1 American physical therapist, 2 Mexican physical therapists, and 11 YEWTHS ROC team members

WHAT: 67 pediatric and adult wheelchairs delivered and fitted

WHEN: March 6 – 16, 2015

WHERE: Distribution sites in Mexico included Guaymas, Benito Juarez, Navojoa, and Vicam
References


