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An Occupational Therapy-Based Education Program for Caregivers of Individuals with Cerebral Palsy: A Culturally Conscious Perspective

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AN OCCUPATIONAL THERAPY-BASED EDUCATION PROGRAM FOR

CAREGIVERS OF INDIVIDUALS WITH CEREBRAL PALSY: A CULTURALLY

CONSCIOUS PERSPECTIVE

By

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Gail Bass, PhD, OTR/L

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PERMISSION

Title   An Occupational Therapy-based Education Program for Caregivers of
               Individuals with Cerebral Palsy in Ghana: A Culturally Conscious
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TABLE OF CONTENTS

ACKNOWLEDGMENTS

ABSTRACT

Introduction

Individuals with cerebral palsy (CP) are able to lead functional, productive, and

fulfilling lives when provided the opportunity. In the country of Ghana, the prevalence of

CP is estimated to be one out of every 300 births (Purple Field Productions [PFP], 2011),

however, a lack of education about CP and other disabilities, limited access to healthcare

services, and scarce resources hamper the Ghanaian people's opportunities for

habilitation (Reynolds, 2010; Tinney, Chiodo, Haig, & Wiredu, 2007). In addition,

cultural beliefs and societal attitudes toward people with disabilities in Ghana pose a

barrier for those individuals to fully participate in occupation.

According to the World Federation of Occupational Therapy (WFOT),

occupational therapists have a responsibility and an opportunity to address occupational

injustices through the development of programs for underserved populations (WFOT,

2006). Occupational therapy (OT) is an established element in the treatment of

impairments and symptoms associated with CP (Steultjens et al., 2004). Often OT

intervention includes parent or caregiver education. Because of the lack of access to

medical care and therapy services, as well as the stigma related with disability, much of

the care of individuals with CP is up to family members or informal caregivers. These

caregivers often do not have access to the training or resources they need (Tinney et al.,

2007).

Purpose

The purpose of this program is to enable caregivers in Ghana with the training and

knowledge of the basic skills and assistive devices to more effectively care for

individuals with CP while enabling those with CP to engage in occupations more independently. It is also intended to empower the caregivers to pass on the skills and knowledge to other caregivers in their communities.

Methodology

A review of literature was conducted including use of professional journals, textbooks, and organizational websites. Topics investigated were Ghana; disability culture, provision of healthcare and resources, and CP in Ghana; OT interventions for individuals with CP; and adult education principles. In addition, data from a needs assessment was obtained to provide a personal perspective for content of the product and targeted audience. Three compatible Canadian occupational behavioral models guided the literature review and development of the product: Person-Environment-Occupation Model, Canadian Model of Occupational Performance and Engagement, and the Canadian Model of Client-Centered Enablement.

Conclusion

Implementation of this program is intended to enable and empower caregivers in Ghana to carry out that role more effectively, in turn improving the occupational performance and engagement of individuals with CP. It is recommended to be used within the curriculum of the University of North Dakota OT Department's international service learning course as pilot program. It is expected the participants of the course will learn the contents of the product, *How to Help a Child with Cerebral Palsy,* before distributing it to and using it as a guide in teaching caregivers in Ghana during the fieldwork portion of the course.

CHAPTER I

INTRODUCTION

Overview

Individuals with cerebral palsy (CP) are able to lead functional, productive, and fulfilling lives when provided the opportunity, which includes access to necessary medical care and therapy services. However, these services are not always readily available to individuals, especially in developing countries such as Ghana. In a country where the prevalence of CP is estimated to be one out of every 300 births (Purple Field Productions [PFP], 2011), individuals with CP face several barriers to gaining independence and participating in meaningful occupations. A lack of education about CP and other disabilities, limited access to healthcare services, and scarce resources hamper the Ghanaian people's opportunities for habilitation (Reynolds, 2010; Tinney, Chiodo, Haig, & Wiredu, 2007). In addition, cultural beliefs and societal attitudes toward people with disabilities in Ghana pose a barrier for those individuals to fully participate in occupation.

Even though research regarding specific occupational therapy (OT) approaches remains inconclusive, OT is an established element in the treatment of impairments and symptoms associated with CP (Steultjens et al., 2004). Unfortunately, along with a shortage of medical facilities there is a significant shortage of trained health professionals in Ghana, which includes a shortage of occupational therapists. Because of these shortages, much of the care of individuals with CP is up to family members or informal

caregivers (Tinney et al., 2007). These caregivers do not often have access to the training or resources they need in order to provide necessary care for individuals with CP. Because parent or caregiver education is regularly a significant aspect of OT services, an OT- based educational manual developed from a culturally competent perspective could benefit Ghanaian caregivers.

The OT-based manual, *How to Help a Child with Cerebral Palsy*, developed through this scholarly project was designed to provide Ghanaian caregivers with basic information regarding the care of individuals with CP. The manual was also designed to be used by OT students completing an international service learning project in Ghana. The students will use the manual to guide the caregivers in applying basic evidence-based techniques in the care of individuals with CP. The anticipated outcome is that caregivers who have been trained to use the manual will be enabled in their abilities to care for individuals with CP, ultimately increasing participation in meaningful occupations and improving occupational performance for both the caregivers and the individuals with CP. It is also hoped that the caregivers who have been trained to use the manual will share what they learned with other caregivers.

In order to ensure the applicability of the proposed manual, multiple factors must be considered and further understood. When it comes to establishing services for people with disabilities in Ghana, the culture of the citizens needs to be considered. Societal perceptions, government involvement, and healthcare access and resources have impacted the quality of life and participation in occupation of individuals with disabilities. The perception of disability in the country is evolving, much in part due to changing legislation and increased awareness; however, traditional customs and beliefs

2

still exist and continue to influence the treatment of individuals with disability. The OT's role in working with individuals with CP has also been examined along with the current evidence regarding OT interventions. This information is included in Chapter II of this document.

In addition to what is in the literature reviewed in Chapter II, more information regarding the therapeutic needs for people with CP in Ghana has been obtained through personal accounts of individuals in Ghana and organizational websites. Information gathered from a representative of a residential school for children with disabilities in Ghana was shared as a collaborative effort to demonstrate the need for services and identify the major concerns for people with CP and their caregivers (E. Kringle & A. Johnson, personal communication, December 7, 2011). Data from the survey mirrored the issues identified in the professional literature that dealt with cultural beliefs and values, social limitations, institutional barriers, and physical needs. The respondent depicted a lack of qualified personnel and services available to their students with disabilities as well as a lack of accessibility, not only due to availability but also cost, distance, and cultural values. The respondent also revealed that many of the caregivers at the school were illiterate, a social barrier in working with the children with disabilities. Lastly, the data illustrated the personal needs of the children with disabilities, focusing on the two occupational areas of self-care and productivity; both were stated to be highly valued in their culture. However, the overall theme recognized throughout the feedback was enabling the children with disabilities to be productive members of their society and accepted as such (E. Kringle & A. Johnson, personal communication, December 7, 2011).

Theoretical Perspective

In conducting this project and creating the final product, the authors looked to three Canadian-based models to guide a part of the process. The Person-Environment-Occupation (PEO) Model, the Canadian Model of Occupational Performance and Engagement (CMOP-E), and the Canadian Model of Client-Centered Enablement (CMCE) were not only chosen for their compatibility in language, global applicability, and attention to social justice, but because of their individual key attributes, which will be discussed in the following sections (Strong et al., 1999; Townsend & Polatajko, 2007).

PEO model

Recognizing that components of the environment, person, and occupation strongly and directly influence individuals' participation and performance in meaningful occupations, the PEO Model was chosen to guide investigation of the topic. The PEO Model conceptualizes the interaction between the person, his/her environment, and the occupations in which he/she engages (Strong et al., 1999). The fit or congruence between these three components (person, environment, and occupation) signifies the individual's occupational performance. Any changes within the person, the environment, or the occupation itself can influence the interaction between the three, thus influencing occupational performance. While other occupation-based models may also take into account the client's environment and occupations, the PEO Model enables the therapist to identify specific processes within the person-environment, person-occupation, and occupation-environment interactions that potentially inhibit or promote the PEO fit. This facilitates the development of interventions targeting the person, environment, or occupation in order to improve the PEO fit and increase occupational performance

4

(Strong et al., 1999). By using the PEO Model to guide further investigation of the experiences of individuals with CP in Ghana, all potential interventions can be explored, and those deemed most beneficial can be implemented.

CMOP-E

The CMOP-E complements the PEO Model in that they share common terminology and both place a strong emphasis on the interaction between person, environment, and occupation (Strong et al., 1999). However, the CMOP-E differs from the PEO Model in that it focuses on occupation beyond performance, highlighting the influence of spirituality and meaning, to include engagement (Townsend & Polatajko, 2007). Through a preliminary review of literature, the authors of this project discovered that there is a strong spiritual influence throughout the Ghanaian culture. Traditional spiritual beliefs and values affect perceptions and treatment of individuals with disabilities, decisions to seek westernized medicine or traditional healing, and ultimately impact the rights of individuals with disability and their opportunity to participate in meaningful occupation. Because of the significance of spirituality in Ghanaian culture, the CMOP-E was incorporated into the development of the educational manual for caregivers. The CMOP-E was also used in structuring the manual around occupation. Using this model, occupation is viewed in terms of purpose within three categories, rather than a hierarchal structure like the PEO Model (Townsend & Polatajko, 2007). The creators of the manual provided the techniques/interventions within the three occupational categories: self-care, productivity, and leisure (Townsend & Polatajko, 2007).

CMCE

While PEO and CMOP-E are theoretical frameworks that describe occupational

performance through dynamic interactions, the CMCE is visual metaphor that illustrates

client-centered enablement through the client-professional relationship and key skills for

enabling individual and social change (Townsend & Polatajko, 2007). According to the

CMCE, enablement is a core competency of occupational therapy practice (Townsend &

Polatajko, 2007). The authors of this project used this model to help guide the

development of the manual, whose main objective is to enable an underserved

population. The ten enablement skills defined in the CMCE (Townsend & Polatajko,

2007) are identified in Figure 1 with examples of how each skill is addressed in the

caregiver manual.

Figure 1.	Linking Enablement Skills to the Caregiver Manual	
Skill	**Definition**	**Project Example**
Adapt	to make appropriate or fitting for a specific use or situation in response to challenges.	• Design the manual to be adaptable to meet the needs of people with varying presentations of CP. • Adapt the selection of evidence-based occupational therapy treatment techniques and learning principles to meet the needs of Ghanaian caregivers and individuals with CP within their physical, social, cultural, and institutional environments. • Adapt the presentation of information to be suitable for the caregivers, based on gathered statistics of literacy level and potential language barriers.
Advocate	to raise critical awareness and promote power sharing; speak out and/or empower others to speak out upon their behalf.	• Distribute the manual to caregivers, empowering them to pass the education and training forward. • Provide a resource list in the

		manual.
		• Use to educate the caregivers about CP and the implications.
Coach	to develop and sustain a partnership with others in which one provides guidance, assistance, and support for them to improve or enhance their performance and quality of life.	• Provide simple, understandable illustrations and text that guide the caregiver through the interventions
		• Use the manual in conjunction with hands-on caregiver training session, where the educator guides the caregiver through interventions with feedback
Collaborate	to share power when working *with* others on issues, mutually respecting professional expertise and personal experience.	• Provide intervention techniques in the manual that combine evidence-based practice and cultural competencies.
		• Intervention techniques in the manual do not apply to all individuals with CP as there is no one presentation of CP; educators work with the caregiver in selecting applicable interventions.
Consult	to confer with experts and/or stake holders to make informed decisions.	• In development, the creators confer with occupational therapy professors and refer to pertinent existing research and literature.
		• During education with caregivers, elicit views and feedback from the caregivers and the individuals with CP.
Coordinate	to organize or synchronize people, activities, events, or resources in a common action or effort.	• Coordinate the distribution and intended use of the manual with service learners and Ghanaian caregivers of people with CP.
		• Coordinate the acquisition of resources and services through information and contacts provided in the manual.
Design/Build	to formulate plans/strategies, create products, and/or construct environments that provide, support, or promote a program, service, or need.	• Develop an evidence-based, culturally competent manual to address the needs of Ghanaian caregivers in providing care to people with CP.
		• Provide designs in the manual to build assistive devices, such as standing frames, chairs, and

		bolsters based on accessible resources.
Educate	to pass on knowledge, skills, and strategies to others based on philosophies and learning theories.	• The manual is an educational tool based on adult learning principles to be used in conjunction with hands-on learning with caregivers to promote the use of evidence-based interventions for people with CP.
Engage	to involve others in active participation.	• Engage students to participate in service learning project. • Engage caregivers in learning the interventions found in the manual. • Empower and motivate caregivers to engage others in meeting the needs of individuals with CP.
Specialize	to use specific techniques in particular situations.	• The manual is based on current evidence-based practice. • The manual incorporates specific frames of reference, such as neurodevelopmental treatment (NDT) handling and positioning techniques and Adult Education principles to guide development.

Adapted from Townsend, E. A. & Polatajko, H. J. (2007). *Enabling occupation II: Advancing an occupational therapy vision for health, well-being, & justice through occupation* (pp. 113). Ottawa, Ontario: CAOT Publications ACE.

In addition to the PEO, CMOP-E and CMCE, several applicable frames of reference were used in guiding the development of the caregiver manual, including neurodevelopmental treatment (NDT), motor learning theory, and the rehabilitation frame of reference. NDT, a commonly used frame of reference used to guide the treatment of children with CP, focuses on the development of normal movement patterns and increased postural control (Cole & Tufano, 2008). Caregivers can be taught specific handling methods, facilitation and inhibition techniques, and positioning principles in

order to optimize the child's functioning in everyday occupations (Butler & Darrah, 2008; Cole & Tufano, 2008).

Motor learning theory is a more contemporary approach to the treatment of children with CP. It focuses less on the normalization of movement patterns and more on finding the most optimal movement pattern specific to each individual, his or her environment, and the task to be performed (Cole & Tufano, 2008). An example would be discovering the optimal way for a child to perform a dressing task. The therapist or caregiver can grade the task or activity to be performed and create a structured learning environment in which the individual can practice performing the task with guidance and feedback. Both the NDT and motor learning approaches have been found to be effective in practice, and it has been suggested they be used together in treatment (Valvanno, 2004). Both approaches were used in the development of the caregiver manual, with NDT principles directing instruction on beneficial handling and positioning techniques, and the motor learning theory providing a broader task-oriented focus.

The rehabilitation frame of reference, a commonly used approach in many areas of OT services, involves the utilization of compensatory strategies or adaptive equipment when remediation of underlying deficits is not possible (Trombly, 2002). For example, a child with CP may use adapted feeding utensils due to impairments in grip strength; or, the child may be taught alternative, one-handed dressing techniques when he or she only has use of one upper extremity. Using compensatory strategies or adaptive equipment can allow individuals with CP to be more independent in occupations (Trombly, 2002). Different strategies and adaptive equipment will be described within the manual.

Finally, because the goal of the manual is to educate and enable caregivers, the process in which adults learn was considered when developing the manual. The authors chose Malcolm Knowles' Adult Learning theory and the Health Belief Model (HBM) to guide their decisions regarding topics to cover and format to use; and to identify and address any potential barriers to learning.

Conclusion

This chapter is an overview of the scholarly project and the theoretical bases that drove the investigation and guided the development of the product. Chapter II of this document is a report of the findings from the review of professional literature. The methodology used to design the product is described in Chapter III, and Chapter IV contains the product in its entirety. Finally, Chapter V is a summary of the project and includes recommendations and limitations.

CHAPTER II

REVIEW OF LITERATURE

Introduction

According to the World Federation of Occupational Therapy (WFOT), occupational therapists have a responsibility and an opportunity to address occupational injustices through the development of programs for underserved populations (WFOT, 2006). Based on perceived occupational injustices for people with cerebral palsy (CP) in Ghana and a preliminary review of the existing literature, the authors explored the physical, cultural, social, and institutional environments to get a contextual understanding of the country, its people, and the interaction between them. The authors looked specifically at the population of people with CP, what occupations they participate in, and how they perform occupations within their environment. In focusing on people with CP, one could not overlook the caregivers' crucial role in occupational engagement. Throughout this chapter, evidence is presented from an investigation of existing literature, organizational websites, and other credible sources indicating that occupational injustices are present in Ghana for people with CP, that occupational therapy interventions for this population exist and promote improved occupational performance, and that caregivers can benefit from education to optimize performance in their roles.

Overview of the Republic of Ghana

The Republic of Ghana, as it is officially named, is a coastal country in western Africa bordered by Côte d'Ivoire to the west, Togo to the east, Burkina Faso to the north,

and the Gulf of Guinea to the south, where its capital city, Accra, sits (Central

Intelligence Agency [CIA], 2011). The current population of Ghana, which stands well

over 24 million, is comprised of people from eight major ethnic tribes who practice three

primary religions and speak 52 different dialects with English being the official language

(CIA, 2011; Reynolds, 2010).

Ghana became the first sub-Saharan colonized African country to gain its

independence in 1957. It was formerly part of the British colony, Gold Coast, a name

that reflected one of its major sources of foreign exchange, along with cocoa (CIA,

2011). Ghana was once considered one of the world's most prosperous tropical countries

until it faced over twenty-five years of mismanaged government, plundered resources,

and rampant corruption in the neo-colonial era (Meredith, 2005). By the 1980s, its

economy was shattered, resulting in increased poverty and crime and disintegrated public

services including transit, education, and healthcare systems (Meredith, 2005). Ghana

was not alone in its struggles. According to Meredith (2005), by the late 1990s more than

half of the African states relied heavily on Western aid to fund government and public

investments despite the effort for an African renaissance for democracy and economic

growth. Into the twenty-first century, Africa as a whole continues to struggle with

poverty, corruption, war, famine, epidemics, illiteracy, and civil unrest. Ghana itself is a

progressing country, yet it still struggles with major social problems, like high rates of

poverty, infant mortality, illiteracy, and limited public services (World Health

Organization [WHO], 2011).

Disability Culture in Ghana

When it comes to establishing services for people with disabilities in Ghana, the culture of the citizens needs to be considered. Societal perceptions, government involvement, and healthcare access and resources have impacted the quality of life and participation in occupation of individuals with disabilities. The perception of disability in the country is evolving, much in part due to changing legislation and increased awareness; however, traditional customs and beliefs still exist and continue to influence the treatment of individuals with disability.

The passage of the Disability Rights Bill of 2006 was a significant step for the country to officially recognize basic rights of people with disabilities and establish binding laws to ensure those rights are protected (Ghana Federation of the Disabled [GFD], 2008). The bill addresses equal rights to employment, education, transportation, and healthcare for people with disabilities and created a National Council on Persons with Disabilities (GFD, 2008). While the laws are in place, barriers remain for implementation of the policies. Reynolds (2010) completed a study that illustrated some of these barriers. One is a lack of awareness by the public of either the existence of the bill or its content. Another is a lack of understanding of the bill, the extent of what constitutes disability rights, and disability in general. Additionally, limited funding and resources pose a barrier to the execution of programs directed by the policy. In order to overcome these barriers, the public or nongovernmental groups need to match the governmental efforts (Reynolds, 2010).

The advocacy organization, GFD (2008), which was established in 1987, has been instrumental in affecting government policies regarding disability, including the passage

of the Disability Rights Bill. Their mission is to create awareness about abilities of

people with disabilities and promote equality of people with disabilities through

advocacy, lobbying, and collaboration (GFD, 2008). Another organization for human

development, Volunteer Service Overseas-Ghana (VSO), compiled a network list of both

government agencies and nongovernmental organizations in the various regions of Ghana

to assist the public and other disability agencies in accessing information and services for

people with disabilities (Tinney, Chiodo, Haig, & Wiredu, 2007). Overall, there are

several nongovernmental organizations that provide education on disability to the public,

run programs for people with disabilities, and advocate for people with disabilities.

The public's involvement in obtaining education about these issues is influenced

by literacy, education level, and access to information. In a study by Andrzejewski,

Reed, and White (2008), the authors found that nearly half of the participants from an

ecologically, socially, and economically diverse region of Ghana were illiterate. The

authors discovered literacy and education level had a significant positive correlation with

knowledge of etiology and prevention of diseases. They were able to conclude that

communities with regular presence of a market place also had a positive correlation to

knowledge of disease, which they attributed to diverse social networking (Andrzejewski

et al, 2008). Social networking as well as broadcast media played an important role in

the acquisition of information regarding healthcare in another study by Hampshire,

Porter, Owusu, Tanle, and Abane (2011). These researchers found Ghanaian youth were

accessing health information, primarily in the form of pharmaceutical advertisements,

through the use of mobile phones and broadcast radio. The information the youth

acquired influenced their decisions to seek healthcare (Hampshire et al., 2011). These

studies imply that informal social networking, whether through public markets or mobile phones, and broadcast radio are important channels for communicating information to the public.

Despite the progress in government policy, advocacy programs, public information, and modern healthcare, traditional customs and beliefs continue to influence perception and treatment of people with disabilities. One example of an influential custom is the spirit child phenomenon. Traditionally, a spirit child or *chichuru* is a spirit that takes human form and is believed to wreak havoc on a family it is born into. An infant may be suspected to be a spirit child based on disability, deformity, or unusual behavior (Allotey & Reidpath, 2001; Denham, Adongo, Freydberg, & Hodgson, 2010). Some of the common physical or behavioral signs at birth of a spirit child are abnormal head size, lumps on his/her back, teeth, clubbed feet, dislocated or broken limbs, complications, and constant crying (Allotey & Reidpath, 2001; Denham et al., 2010). Up to 15% of infanticide can be attributed to the spirit child phenomenon, as death is understood to be the only effective means to protect the family (Allotey & Reidpath, 2001). The spirit child phenomenon is complex in terms of diagnosis, but demonstrates how traditional spiritual beliefs may influence the view and treatment of people with disabilities (Denham et al., 2010). In a study conducted by Reynolds (2010), community leader participants supported the popular notion that disability was a result of spiritual influences despite their own perceptions of disabilities being caused by environmental or medical factors. Other researchers concluded that the prevalence of the spirit child phenomenon is connected to core public health issues of the region like poverty, food

insecurity, limited healthcare, minimal support for children who are disabled, and lack of prenatal/neonatal care and education (Denham et al., 2010).

Perceptions or misconceptions that disability is caused by spiritual intervention brings with it social stigma, including beliefs that the disability is contagious or a curse on the individual or the whole family (Reynolds, 2010). The stigma negatively affects people with disabilities participation within their families as well as in society through education and employment. Kassah (2008) noted that families give preferential treatment to their children without disabilities when it comes to education because of social prejudice rather than seeing the need to educate all of their children and give those with disabilities a chance at a meaningful and productive life. The barriers and social discrimination against people with disabilities has led to their embarrassment at school, harassment at work and fear of peoples' reactions (Kassah, 2008). Many people believe the only way that people with disabilities are capable of earning a living is to beg for money on the streets (Kassah, 2008; Reynolds, 2010). However, research has reflected that many Ghanaians have not actually interacted with people with disabilities and do not look beyond prejudices and old cultural beliefs. Those who have had positive interactions with people with disabilities carry a realistic perception of them as capable citizens (Reynolds, 2010).

The enmeshment of traditional beliefs and modern medicine also continues to impact healthcare in Ghana. The study by Hampshire et al. (2011) reflected that Ghanaian youth were utilizing the modern healthcare systems. There has been evidence of younger generations seeking modern healthcare over traditional healing first, but they may continue to use traditional means because of family expectations, cost, access, or

effectiveness of modern medicine (Allotey & Reidpath, 2001; Tabi, Powell, & Hodnicki, 2006). A case study by Allotey and Reidpath (2001) illustrated how these intertwine. One participant described her experience seeking modern medicine for the delivery and care of her baby. She had complications throughout her pregnancy and delivery due to a heart condition, but was in stable condition after delivery. During the night in the hospital, the grandmother of the baby fed the infant an herbal concoction, a customary ritual to handle *chichuru,* which resulted in the infant's death. The participant explained that her mother believed this was a spirit child due to all of the complications and she was doing the right thing based on her spiritual beliefs and customs; however, the participant, who didn't believe in *chichuru,* wondered how this could be allowed in a hospital (Allotey & Reidpath, 2001). Traditional beliefs also impact the choices made by people who work in healthcare. In the case study, the midwife and most of the nurses in the hospital were local and observed the same traditional customs (Allotey & Reidpath, 2001).

Donkor and Andrews (2011) conducted a study of Ghanaian nurses and found that some of their local customs matched universally accepted international principles, while others clashed causing tension and ethical dilemmas. It is imperative that healthcare workers not only understand the cultural beliefs of the population they are serving, but understand their own biases and the professional code of ethics which they have agreed to uphold.

Provision of Healthcare and Resources in Ghana

In 2003, the Ghanaian government passed the National Health Insurance Act to guide such things as the provision of basic healthcare services to residents through

17

mutual and private health insurance schemes, the regulation of the schemes, the accreditation and monitoring of associated health care providers, and the funding and subsidies for government sanctioned district programs and exempt groups. According to Jehu-Appiah et al. (2010), the National Health Insurance Act was passed to fulfill a campaign promise "to eliminate user fees...and improve access to health care especially for the poor and vulnerable" (p. 158). The National Health Insurance Act (2003) led to the creation of the National Health Insurance Scheme (NHIS), a combination of both social and mutual health insurance programs that is funded through public revenues, contributions to social security funds, and income-adjusted premiums. These monies reinsure the government sponsored District Mutual Health Insurance Schemes and cover the premiums for exempt groups (National Health Insurance Act, 2003). The exempt groups include expectant mothers, children under the age of 18 years, individuals 70 years or older, people contributing to or on social security pensions, and "indigents" (NHIS, 2010).

In the National Health Insurance Regulations of 2004, an instrumental document to the NHIS legislation, it is stated that people shall not be discriminated against in regards to admission for membership or between members based on personal factors including disability (LI 1809, Reg. 16, 2004). The Disability Rights Act of 2006 also supports the rights of people with disabilities to healthcare. The writers of the Disability Rights Act outlined that the Ministry of Health shall create policies to support free medical treatment for people with total disability, to train health professionals for rehabilitation services, to provide disability education in healthcare programs, to periodically screen children for the purposes of detection, prevention, and management of

disability, and to establish assessment centers in each district for early detection and intervention of disability (Persons with Disability Act, 2006).

The Ghanaian government demonstrated progressive efforts through legislative action to improve healthcare programs and access, yet the literature points out limitations through healthcare personnel and accessible resources. Between 2000 and 2010, Ghana averaged 0.9 physicians and 10.5 nurses or midwives for every 10,000 residents as compared to 26.7 and 98.2 respectively in the United States (WHO, 2011). The ratio of other healthcare service providers to residents was 0.8:10,000, which was over 30 times fewer than in the United States (WHO, 2011). The lack of qualified healthcare personnel impedes access to healthcare in Ghana, not only for persons with disabilities but for the population as a whole (Olusanya, 2011; Tinney et al., 2007).

Along with the shortage of healthcare personnel, limitations on access to healthcare are set by facilities, locality, and cost. Ghana is limited in what facilities and services they can offer (Tinney et al., 2007), and accessing them is an extra challenge for 49% of the country's population who live in rural areas (WHO, 2011). In their study, Tabi et al. (2006) found their participants believed that greater poverty and isolation from healthcare facilities exist in the rural areas, making access to modern healthcare less likely for this portion of the population. After the time and expense of getting to a facility, the medical treatment is unaffordable (Tabi et al., 2006). The NHIS provides cost exemptions for "indigents", or the poorest poor, but residents living under the poverty line who do not qualify as "indigents" are still expected to pay at least the renewal and processing fees for insurance and possibly the annual premiums (NHIS, 2010). Jehu-Appiah et al. (2011) studied the enrollment in the NHIS and found inequity

between the poor (lower enrollment) and the rich (higher enrollment). They discovered negative perceptions of cost were a major factor that decreased people's likelihood of enrolling or sustaining membership despite receiving benefits or quality care (Jehu-Appiah et al., 2011).

On the other hand, Hampshire et al. (2011) reported that Ghanaian youth were accessing healthcare more because they were able to use their family's NHIS card for payment. They heard about treatments and pharmaceuticals via phones, radio, and social networks, and found means, like asking for transportation, doing work for pay, etc. to get to the healthcare centers for treatment or medications (Hampshire et al., 2011). Residents who could not afford to or were otherwise unable to access modern medicine were more likely to turn to traditional healers within their communities (Tabi et al., 2006).

Cost and proximity were not the only factors influencing access to healthcare; education, religion, and culture also contribute to taking the initiative to access it. In 2008, about 66% of Ghanaian adults were literate (WHO, 2011). Literacy and education level were found to directly correlate to increasing health knowledge and play a significant role in attaining health services, be it modern or traditional medicine (Andrzejewski et al., 2008; Tabi et al., 2006). Spreading information through the spoken word via radio, social networking, etc. has demonstrated a positive effect on health knowledge and services offered despite the illiteracy rate (Andrzejewski et al., 2008; Hampshire et al., 2011). Individual's religion or culture has also impacted what healthcare they access. Tabi et al. (2006) reported that people of certain religions sought modern medicine over traditional healing as they associated it with demonic influences,

while others were influenced, even pressured by family and friends to seek traditional medicine because of their culture.

Culture continues to play a major role in healthcare access especially for people with disabilities. With many barriers to healthcare services already in place, the burden of care is placed upon informal caregivers, family or community members, who spend the most time with the individuals caring for their daily needs. Informal caregiving requires physical, emotional, financial, and time demands, but in societies like Ghana, where disability is stigmatized, the family caregiver may face social stress as well (Denham et al., 2010; Hamzat & Mordi, 2007). The individuals being cared for, particularly children with disabilities are at a greater risk of abuse, neglect, or isolation due to the cultural beliefs toward disability, and they may not get the health care they need (Hamzat & Mordi, 2007; Oluasnya, 2011).

<div align="center">Cerebral Palsy in Ghana</div>

Like in other developing countries, there is no accurate account of the prevalence of CP in Ghana. Dr. E. Badoe, Director of Neurology/Development Service at the University of Ghana Medical School stated that a fair estimate of occurrence of CP in Ghana is in one out of every 300 births compared to 2:1000 in the developed world (Purple Field Productions [PFP], 2011). While the efforts of nongovernmental organizations and the passage of the Disabilities Rights Act promote education about and equality for people with disabilities, the individuals with CP face the same stigma that exists in the country toward people with disabilities in general. Often the children with CP are kept home out of fear and shame, implications on the family, lack of hope, and insufficient knowledge about the diagnosis, interventions, and prognoses (Cerebral Palsy

Africa, n.d.; Reynolds, 2010). The isolation of children with CP results in being denied

proper healthcare and education, which strongly impacts their future psychosocially and

economically. There is a high prevalence of people with disabilities resorting to begging

for a living due to lack of educational and/or vocational opportunities afforded to them

(Kassah, 2008; Reynolds, 2010). They not only do it for financial gains, but also for the

gratification of engaging in work and contributing to their families (Kassah, 2008).

The cost of living with CP is high in terms of financing and accessing healthcare

as well as the impact it has on the individuals with CP and their families. The shortage of

facilities, services, and qualified personnel in Ghana significantly limits where and when

individuals with CP can acquire the services they need. Tinney et al. (2007) reported

there were no inpatient rehabilitation facilities in Ghana at the time of their study. They

also found a significant shortage of trained physiatrists; occupational, physical, and

speech/language therapists; orthotists; and prosthetists throughout the country. The

authors attributed this to the lack of education programs and qualified faculty, negative

attitudes toward disability, and the prioritization of medical emergencies, infectious

diseases, and mortality rates over rehabilitation (Tinney et al., 2007). According to Dr.

Badoe, the regional and teaching hospitals are the only facilities where rehabilitation

services are offered (PFP, 2011). Without living within close proximity to the facility,

families struggle to access the services. One mother carried her son with CP on her back

great distances because lack of access to near-by services, transportation, or mobility

equipment (PFP, 2011). Even though the government provides a 90% subsidy, the cost

of prosthetics, orthotics, and assistive equipment were unaffordable to most Ghanaians

(Tinney et al., 2007). There are nongovernmental organizations that sponsor adaptive

equipment workshops where volunteers learn to make the equipment out of inexpensive, available resources like cardboard and newspaper (Cerebral Palsy Africa, n.d.; PFP, 2011; People Potential, n.d.). Access to services and affordable equipment makes it possible for children with CP to engage in their environments, learn, and participate in occupations. One mother of a child with CP described her child being able to go to school after receiving therapies, which also enabled her to return to work and contribute financially to her family (PFP, 2011).

With therapeutic services and proper equipment, people with CP can lead functional and productive lives (PFP, 2011). While some Ghanaians accept the idea of people with disabilities attending school and working, they are skeptical that they will be able to perform at an equal level to people who are non-disabled (Reynolds, 2010). One woman with CP, who worked as the head of the Industrial Technology (IT) department at a financial services company in Ghana and held a degree in Computer Science and two in IT, stated that she is fortunate for having had the opportunity to receive therapy services beginning at a young age. She acknowledged that if she had lived in Ghana then, things probably would have been different (PFP, 2011). According to Sandra Carsamer, Paediatric Physiotherapist, Korle Bu Teaching Hospital, "Children with cerebral palsy are unique people. They are very intelligent and, given the chance, they can be able to participate in their community as much as anybody else" (PFP, 2011).

Occupational Therapy Intervention with Individuals with Cerebral Palsy

CP is a nonprogressive neurological disorder of movement and posture, resulting from a prenatal malformation of or peri- or postnatal damage to the central nervous system (Odding, Roebroeck, & Stam, 2006). Risk factors associated with the occurrence

23

of CP include low or very low birthweight, intrauterine or neonatal infections, severe

jaundice, and birth asphyxia (Odding et al., 2006). The presentation of the child's

impairment depends on the location of the brain abnormality. A lesion located in the

motor cortex results in spastic CP; a lesion in the basal ganglia results in athetosis, or

fluctuations in tone; and damage to the cerebellum indicates ataxia. Secondary

impairments associated with CP include cognitive or intellectual deficits, epilepsy or

other seizure disorders, problems with vision or hearing, speech and language

impairments, and gastrointestinal and feeding problems (Odding et al., 2006).

The treatment of individuals with CP in the United States often involves the

contributions of multiple disciplines including physicians, nurses, social workers,

physical therapists, speech language pathologists, orthotists, and occupational therapists.

The child and his or her family should also be considered an integral part of the treatment

team according to principles of family-centered care. Occupational therapy services

provided to individuals with CP focus on the child gaining independence in daily

activities including play, self-care, and educational tasks (Geyer, Kurtz, & Byarm, 1998;

Steultjens et al., 2004). Just as the presentation of symptoms and impairments associated

with CP can vary greatly between individuals, so too does the treatment provided.

Interventions may be aimed at remediating or compensating for the motor, cognitive,

and/or sensory impairments affecting the individual. Interventions that focus on

changing the task or environment, rather than the child, have also been found to be

effective in improving occupational participation (Law et al., 2011). Possible

occupational therapy interventions may include neurodevelopmental treatment,

sensorimotor or play activities, skill training in daily activities, seating or positioning

interventions, splinting, the use of assistive devices or equipment, and education of the parents or caregivers.

Neurodevelopmental treatment (NDT), originally used for the treatment of hemiplegia caused by stroke, has become a commonly used frame of reference to guide the treatment of children with CP (Cole & Tufano, 2008). The goals of NDT when used with children with CP include the development of normal movement patterns and increased postural control. Abnormal tone, reflexes, or movement patterns are addressed through the use of specific handling methods, facilitation and inhibition techniques, hand placement at key points of control, and positioning the child in ways that inhibit certain primitive reflexes or normalize tone (Butler & Darrah, 2008; Cole & Tufano, 2008). Parents or caregivers may also be taught handling, facilitation, and inhibition techniques as necessary for assisting the child with everyday activities (Cole & Tufano, 2008).

Research on the effectiveness of the use of NDT when treating children with CP is inconclusive (Butler & Darrah, 2001). In an evidence report put forth by the American Academy of Cerebral Palsy and Developmental Medicine (AACPDM), evidence regarding NDT was found to be inconsistent, with a number of studies supporting the use of NDT, some showing no significant differences between NDT and control interventions, and some favoring the use of the control interventions over NDT (Butler & Darrah, 2001). Determining the effectiveness of NDT in experimental studies is difficult due to the number of factors which cannot be controlled, including the skill level of the therapist administering treatment, the children's families or caregivers, and the children themselves. In addition, NDT techniques are commonly used along with other therapy

and medical approaches, which can further complicate the evaluation of NDT

effectiveness in research (Butler & Darrah, 2001).

In contrast to the use of an NDT approach, a more contemporary motor learning

and task-oriented approach has been proposed for the treatment of children with CP. In

this systems based approach, motor learning involves the individual finding the optimal

movement strategy to complete a desired task, based on interaction between the

environment, task, and the person (Cole & Tufano, 2008). In a study comparing task-

oriented intervention to NDT with regards to improving sitting balance in children with

spastic diplegic CP, both approaches were found to be effective at increasing postural

control (Chol, Lee, & Ro, 2011). Valvano (2004) suggests the integration of motor

learning principles and activity focused interventions with interventions targeting the

underlying impairments. Impairment-focused interventions may include NDT facilitation

and inhibition techniques targeting abnormal tone, while activity-focused interventions

may include structured practice of a functional task, such as dressing.

Guidetti and Söderback (2001) described occupational therapy services provided

to children with CP in Kenya. Intervention included repeated practice of

dressing/undressing tasks, as well as different play activities aimed at remediating

underlying impairments in fine and gross motor abilities and balance. In addition,

modifications or adaptations to the task or environment were considered when possible,

consistent with a task-oriented or systems based approach (Guidetti & Söderback, 2001;

Cole & Tufano, 2008). Another variation of task-oriented motor learning that is now

used with children with CP is constraint-induced movement therapy (CIMT). Aarts,

Jongerius, Geerdink, van Limbeek, and Geurts (2010) found that modified-CIMT

followed by bimanual task-specific training was effective in improving upper extremity

functioning and increasing the spontaneous use of the affected limb in children with

unilateral spastic CP to participate in play and self-care activities. Both of these studies

emphasized the importance of including meaningful occupations such as play or self-care

in therapy.

Positioning of a child with CP can also greatly affect the child's upper extremity

functioning and engagement in occupations. Adaptive seating devices that provide

postural support have been found to increase children's ability to engage in daily

activities such as self-care and play (Rigby, Ryan, & Campbell, 2009). Many children

with CP, especially those with diplegia or tetraplegia, may require the use of a

wheelchair. In a review of studies examining the effects of positioning on upper

extremity functioning, Stavness (2006) found that children with CP should be put in a

functional sitting position (FSP) when fitted for a wheelchair in order to improve upper

extremity functioning. A FSP includes symmetrical alignment of the head, neck, and

trunk, a body orientation in space of 0-15 degrees, a hip-belt to neutralize the pelvis, an

abduction orthosis, and footrests (Stavness, 2006).

Proper positioning of the child may be particularly important during feeding.

Providing trunk support and correcting postural alignment is the first step in improving

oral-motor skills (Case-Smith & Humphrey, 2005). Abnormal tone, weak oral motor

control, and oral hypersensitivity can also cause feeding difficulties for children with CP.

Intervention may include facilitation and inhibition techniques to normalize tone in

preparation for feeding, oral motor strengthening exercises, and oral desensitization

activities (Case-Smith & Humphrey, 2005; Mueller, 1997). Parent or caregiver education

and involvement with feeding interventions is essential to successful feeding. Clawson, Kuchinski, and Bach (2007) studied the effects of an interdisciplinary pediatric feeding program that utilized oral motor strengthening exercises, proper head and body positioning, behavioral interventions to reinforce positive feeding behaviors, and parent education. Results of the program included an increase in oral intake of food, positive mealtime behaviors, and improved nutrition and weight gain. Caregivers also improved their skills in feeding their children (Clawson et al., 2007). As a child transitions to self-feeding, adaptive devices such as built-up handles on utensils and adapted drinking cups may assist the child in becoming more independent (Mueller, 1997).

In addition to the adaptive devices used for feeding and positioning needs, assistive technology devices may facilitate a child's occupational participation in the areas of communication, mobility, education, leisure and self-care activities (Burstein, Wright-Drechsel, & Wood, 1998; Østensjø, Carlberg, & Vøllestad, 2003). Alternative and augmentative communication devices range from simple picture boards to computerized systems with speech production devices. Assistive devices meant to facilitate mobility can include walkers, crutches, and/or manual or powered wheelchairs or scooters. In addition, equipment such as supine standers, adapted seating devices, or sidelyers can be used to improve the child's functioning while in a static position. In the educational setting, simple devices such as a pencil grip may be utilized to aid in writing tasks. Devices may be low-tech and inexpensive, such as the built-up utensil handles, or more high-tech, such as a motorized wheelchair. As advances are made in technology, devices become more high-tech and expensive. Whether low-tech or high-tech, the

ultimate goal of assistive technology devices is to improve the capability of an individual to perform functional tasks (Burstein et al., 1998).

Use of assistive technology devices depends upon the child's and family's needs and goals for functioning, the availability and affordability of a device, and the ease of use of the device. Østensjø et al. (2003), who studied a group of children with CP ranging in age from two to seven and a half years old, found that the extent of a child's gross motor impairment related to the child's need for caregiver assistance and/or the use of assistive devices in the performance of functional tasks. Children with more severe motor disabilities tended to use more assistive devices for mobility, self-care, and social functioning (Østensjø et al., 2003). Assistive devices must be matched to the specific child, as well as the family or caregiver's needs to ensure the device is affordable and accessible, as well as easy to use in the family's daily routine (Rigby et al., 2009).

Occupational therapists may also use splinting to improve a child's participation in occupation. A splint can be used to put a child's hand in a functional position or to prevent or correct contractures or deformities (Geyer, Kurtz, & Byarm, 1998). Splints can be dynamic, allowing the child some voluntary control over wrist and hand movement, or static, immobilizing the involved joint (Burtner et al., 2008). In a study conducted by Burtner et al. (2008), the effects of static, dynamic, or no splinting on a child's grip and pinch strength, manual dexterity, and muscle activation were examined. Results indicated that the children with CP displayed greater grip strength and manual dexterity when wearing the dynamic splint, but greater pinch strength when wearing no splint. This implies a child may experience greater functional hand use when wearing a dynamic splint. Another important finding was that while wearing the static splint,

children with CP showed decreased muscle activation of wrist and forearm musculature, but increased shoulder muscle activation. This finding suggests that wearing a static splint for extended periods of time has the potential to cause muscle atrophy of the wrist and forearm musculature and fatigue or overuse of the shoulder musculature. While splinting can be effective in improving hand function of a child with CP, splint application and use should be monitored closely by the occupational therapist (Burtner et al., 2008).

With the amount of care a child with CP may require outside of therapy or medical treatment, parent or caregiver education is a significant aspect of occupational therapy services. Parents or caregivers may be educated on how to assist their child in participating in occupations through handling or positioning techniques, specific feeding interventions, and/or use of assistive technology devices or splints. The demands of caring for a child with CP can negatively affect the mental and physical health of a caregiver or parent (Byrne, Hurley, Daly, & Cunningham, 2010). Thus, education should also address caregiver health, possibly covering topics such as time or stress management and participation in other health-promoting activities (Finlayson, Garcia, & Preissner, 2008). Specific to the Ghanaian population, the stigma faced by caregivers of individuals with disability must be addressed (Mwinituo & Mill, 2006).

<div align="center">Adult Education Principles</div>

In general, when educating clients or caregivers many factors must be taken into account, including the different learning styles of children and adults. Malcom Knowles' Adult Learning Theory, as described by Dreeben (2010), proposes that adult learning takes place when the knowledge or skills to be gained relate to life experiences and/or

address a problem or goal. Adult learners are often intrinsically motivated and self-directed, and it is the job of the teacher or therapist to facilitate learning. In addition to these adult learning principles, additional factors to be considered during the teaching and learning process include the learner's culture, literacy level, language, learning style preferences, motivation, and readiness to learn (Dreeben, 2010).

Finlayson et al., (2008) described a process for developing caregiver education, emphasizing identifying the needs of the client and caregiver, using evidence-based practice, and choosing a theory or model to guide the delivery of the education. In addition to identifying appropriate adult learning theories, the authors explored health education and promotion models as the broader goal of caregiver education is to optimize the health and well-being of both the caregiver and client (Finlayson et al., 2008).

Models or approaches to health education provide an explanation for what motivates learning and behavior change as well as identifying variables that may impact learning. One such model is the Health Belief Model (HBM), which describes the interaction between an individual's beliefs about health and about his or her own health behaviors (Berkeland & Flinn, 2005; Reitz, Scaffa, Campbell, & Rhynders, 2009). According to the HBM, the individual first must perceive a health threat or consequence and then weigh the perceived benefits of health education and behavior changes against the perceived barriers to implementing such changes. A caregiver or client must believe that he or she will benefit from taking part in the learning process, as well as having the self-efficacy, or belief in his or her own ability to carry out the recommended behavior changes. The therapist's role is then to highlight the seriousness of the health threat and the significance of the benefits of the intended education, address potential barriers to

learning, and support the individual's self-efficacy to apply what was learned (Berkeland & Flinn, 2005; Reitz et al., 2009).

Conclusion

The literature supports a need for occupational therapy programs in Ghana to serve this population better. Through the review, attention has been drawn to the environmental factors that impact the occupational performance of people with CP. The authors were especially cognizant of the spiritual thread seen in Ghanaian culture that spans through the person, environment, and occupation. Occupational therapy interventions used with people with CP were investigated while critically considering the effectiveness and feasibility to be used by caregivers in their environment. Finally, the authors of this document looked at principles of adult education to gain an understanding of best practices for communicating new skills and information to adult learners. Supported by their findings, the authors propose that a culturally competent caregiver education program will optimize on-going enablement of both caregivers and people with CP participating in meaningful occupations within their own environment.

Chapter III of this document describes the methodology used to design the caregiver education manual. Chapter IV contains the manual in its entirety, and Chapter V is a summary of the project and includes recommendations and limitations.

CHAPTER III

METHODOLOGY

The problems that drove this scholarly project are a lack of education regarding cerebral palsy (CP), limited access to services and resources, and stigma associated with CP in Ghana. Specifically, caregivers of individuals with CP lack sufficient training to provide care that would enable these individuals to fulfill meaningful occupational roles. Based on these problems, the authors focused on developing a product to meet the educational needs of these caregivers.

To better understand these problems, a review of literature was performed. The authors looked at research articles, textbooks, and organizational websites focused on the target population and environment. In addition, information based on a needs assessment was obtained to provide a personal perspective for content of the product and targeted audience. Information gained from this process was used in the development of the product.

In creating the product, the authors looked at multiple factors regarding the person, environment, and occupation. They found literacy rates and language dialects to be potential barriers; therefore they minimized the amount of text used within the manual and utilized simple illustrations to communicate instruction. Considering caregivers' lack of technical skill, the authors selected basic occupational therapy-based (OT) techniques to be covered within the manual. Techniques selected are for the caregiver to efficiently position, handle, and transfer the individual with CP.

The manual was designed to be used as a tool to educate caregivers within their own environment, which includes the physical, social, institutional, and cultural contexts. The manual includes instructions for building assistive equipment using materials and resources known to be available within the physical context. The manual also provides a perspective of people with disabilities as having the potential to be capable, productive human beings, in contrast to the current social stigma against people with disabilities. Use of the manual will help enable caregivers to effect change in their communities.

The manual is structured around the different occupations reported to be valued within the culture, including the areas of self-care and productivity (E. Kringle & A. Johnson, personal communication, December 7, 2011; Kassah, 2008). The techniques are illustrated within the context of occupational performance. This tool helps enable the person to carry out his or her occupational role of caregiver.

The authors used several occupational behavior models and frames of reference to complete this scholarly project. As discussed in Chapter I, compatible Canadian-based models guided both the investigation and the development of the product. The Person-Environment-Occupation (PEO) Model (Strong et al., 1999) was employed to guide the examination of professional literature and other credible sources. The Canadian Model of Occupational Performance and Engagement (CMOP-E) and the Canadian Model of Client-Centered Enablement (CMCE) (Townsend & Polatajko, 2007) were utilized to develop the product.

In addition to the occupational behavior models mentioned above, relevant frames of reference were used in selecting treatment techniques and/or interventions to be included within the product. The manual describes different neurodevelopmental

treatment (NDT) positioning principles and handling techniques to be utilized by

caregivers, allowing abnormal tone and movement patterns to be addressed (Cole &

Tufano, 2008). Rather than presenting NDT principles in isolation, the different handling

and positioning techniques are illustrated within the context of the tasks or occupations to

be performed by the individual. In this way, a motor learning or task-oriented approach

also helped to guide the development of the product, focusing the information provided

on functional tasks, rather than only the child's underlying impairments (Cole & Tufano,

2008). In accordance with the rehabilitative frame of reference, various compensatory

strategies and adaptive devices were also included within the manual to increase the

child's independence when underlying impairments cannot be remediated (Trombly,

2002).

Lastly, adult learning principles, including Knowles' Adult Learning theory

(Dreeben, 2010) and the Health Belief Model (HBM) (Berkeland & Flinn, 2005; Reitz,

Scaffa, Campbell, & Rhynders, 2009), were considered in the way information was

communicated within the manual. Consistent with Knowles' Adult Learning principles,

the caregivers' language, varying literacy levels, and culture were considered when

choosing to minimize the amount of text in the manual and utilize simple illustrations.

The HBM highlights the need for the individual or group being educated to understand

the benefits of utilizing the new information, as well as feeling that they have the

capability to carry out newly learned health behaviors (Berkeland & Flinn, 2005; Reitz et

al., 2009). By coupling use of the manual with guidance from occupational therapy

students and practitioners, potential barriers to utilizing the information presented within

the manual may be addressed and caregivers would have the opportunity to ask questions and try proposed interventions.

This chapter provided a detailed description of the process taken by the authors to complete the scholarly project. Following a review of literature and the application of various occupational behavior models and frames of reference, an occupational therapy based caregiver education manual was created. Chapter IV of this document contains the manual in its entirety, and Chapter V is a summary of the project and includes recommendations and limitations.

CHAPTER IV

PRODUCT

The product of this scholarly project, *How to Help a Child with Cerebral Palsy*, is an occupational therapy-based (OT) educational manual for Ghanaian caregivers of individuals with cerebral palsy (CP). The purpose of this program is to enable caregivers in Ghana with the training and knowledge of basic skills and assistive devices to more effectively care for individuals with CP while also enabling those with CP to engage in occupations more independently. In addition, it is intended to empower the caregivers to pass on the skills and knowledge to other caregivers in their communities. It is recommended that the manual be used within the curriculum of the University of North Dakota OT Department's international service learning course as a pilot program. It is expected the participants of the course will learn the contents of the product, *How to Help a Child with Cerebral Palsy,* before distributing it to and using it as a guide in teaching caregivers in Ghana during the fieldwork portion of the course.

The manual begins with brief messages to occupational therapy practitioners and caregivers who use *How to Help a Child with Cerebral Palsy*. The messages state the intent of the manual and describe the content included. *How to Help a Child with Cerebral Palsy* consists of four sections: "Presentations of Cerebral Palsy", "Body Structures and Positioning", "Self-Care", and "Productivity". "Presentations of Cerebral Palsy" illustrates children with CP displaying common symptoms of the disability. Children with hypotonicity, hypertonicity, hemiplegia, athetosis, and ataxia are shown

along with written descriptions of characteristics associated with each presentation. "Body Structures and Positioning" identifies and defines key points of control for handling a child with CP, as well as positioning principles to be followed. Again, illustrations and text are used to communicate information in this section. "Self-Care" contains the subsections of Functional Transfers and Mobility, Dressing, Feeding, and Sleep. "Productivity" includes the subsections of Housework, School, and Play. Each subsection addresses different self-care or productivity occupations, describing basic handling and positioning techniques and assistive devices that may be used to enable the caregiver to fulfill his or her role and to help the child gain more independence in these occupations. A resource list is provided to caregivers and practitioners, identifying supportive organizations. Finally, a reading and video list is provided, citing texts and video which offer further information on the topic of caring for individuals with CP.

The Person-Environment-Occupation (PEO) Model, Canadian Model of Occupational Performance and Engagement (CMOP-E) and the Canadian Model of Client-Centered Enablement (CMCE) guided the entire process through the development of the product. Neurodevelopmental treatment (NDT), motor learning theory, and the rehabilitation frame of reference influenced the selection of interventions in the manual. Lastly, principles of Knowles' Adult Learning theory (Dreeben, 2010) and the Health Belief Model (HBM) (Berkeland & Flinn, 2005; Reitz, Scaffa, Campbell, & Rhynders, 2009) were applied in determining presentation of the material. These considerations are evident in the following product.

How to Help a Child with Cerebral Palsy
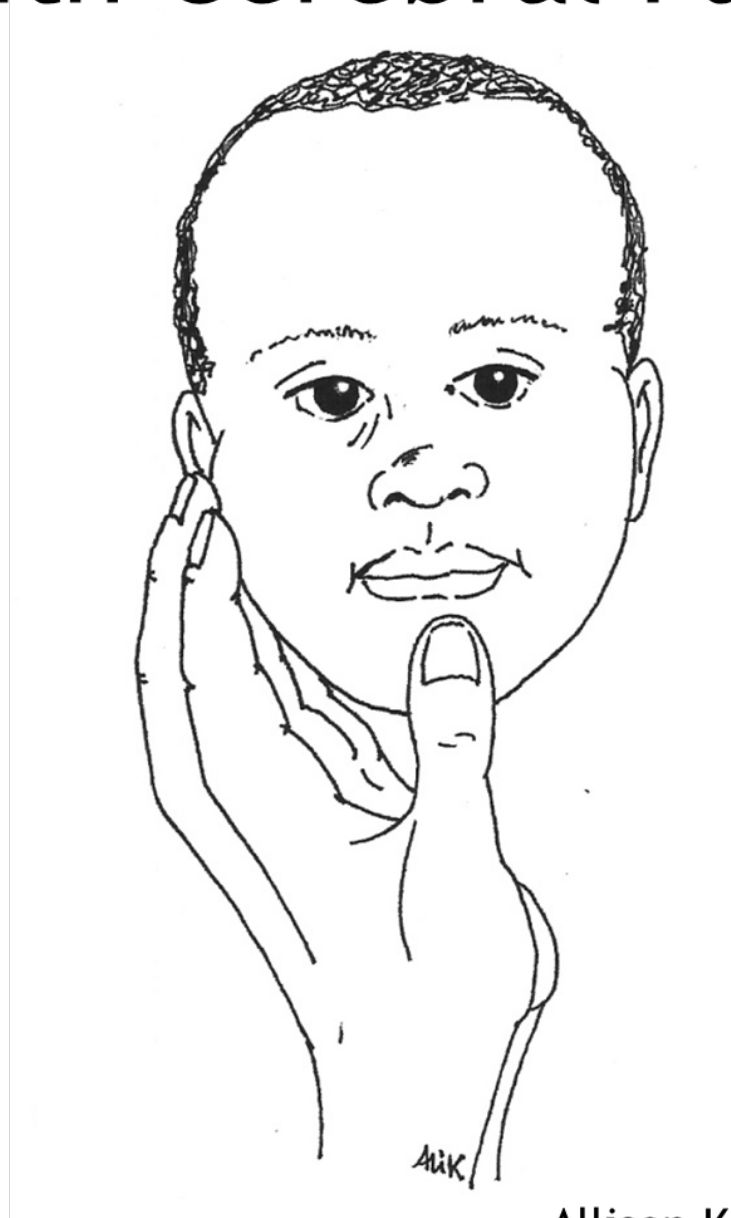
Allison Kalb, MOTS
Diana Huettl, MOTS
Gail Bass, PhD, OTR/L

How to Help a Child with Cerebral Palsy

By

Allison L. Kalb, MOTS
Diana L. Huettl, MOTS
Gail Bass, PhD, OTR/L

TABLE OF CONTENTS

To the Occupational Therapy Practitioners

How to Help a Child with Cerebral Palsy was developed to provide

Ghanaian caregivers with basic intervention techniques and resources

regarding the care of individuals with CP. The intent is that the manual be

delivered to caregivers along with hands-on training from skilled

occupational therapy practitioners. It is also expected that this will enable

the caregivers to care for individuals with CP more effectively and to pass

forward the knowledge and skills to other caregivers. Therefore, each OT

practitioner should use *How to Help a Child with Cerebral Palsy* not only as

a learning tool to familiarize oneself with the featured techniques, assistive

devices, and resources prior to interaction with caregivers, but also as a

guide during instruction with the caregivers. Also, it should be noted that

How to Help a Child with Cerebral Palsy is not a treatment protocol

applicable to every child with cerebral palsy, but rather a guide containing

various evidence-based interventions within occupational contexts that may

suit one to all various presentations of CP, such as ataxia, athetosis, or

hemiplegia. Interventions should be selected appropriately on an individual

basis.

How to Help a Child with Cerebral Palsy was developed based on a

review of the literature and research regarding the social, cultural, physical,

and institutional contexts of Ghana, accepted techniques as occupational

therapy interventions for people with cerebral palsy, and adult education

principles. The theoretical basis of *How to Help a Child with Cerebral*

Palsy is a combination of three Canadian-based models: the Person-

Environment-Occupation (PEO) Model, the Canadian Model of

Occupational Performance and Engagement (CMOP-E), and the Canadian

Model of Client-Centered Enablement (CMCE), which were selected for

their compatibility in language, global applicability, attention to social

justice, and individual key attributes (Strong et al., 1999; Townsend &

Polatajko, 2007).

Strong, S., Rigby, P., Stewart, D., Law, M., Letts, L., & Cooper, B. (1999). Application of the person-environment-occupation model: A practical tool. *Canadian Journal of Occupational Therapy, 66*(3), 122-133.

Townsend, E. A. & Polatajko, H. J. (2007). *Enabling occupation II: Advancing an occupational therapy vision for health, well-being, & justice through occupation* (pp. 113). Ottawa, Ontario: CAOT Publications ACE.

To the Caregivers in Ghana

How to Help a Child with Cerebral Palsy is a book of basic things you can do to help children with cerebral palsy (CP) and make taking care of them easier on you. CP is caused by damage to the brain before or at birth, and the damage will not get worse over time. However, because of the damage, children with CP do not have the same control of their body as other children. This can affect their:

- posture (how they sit, stand, lie down);
- movement (how they use their arms, hands, legs, head, eyes, mouth, etc.);
- cognition (ability to learn);
- behavior (how they act); and
- sensation (how they detect sound, smell, taste, etc.).

Because of this, children have difficulty with things like self-care, housework, play, school, etc. It also makes taking care of the children harder. *How to Help a Child with Cerebral Palsy* focuses on things you can do to help a child with CP do more on their own. While the book does not focus on sensation, behavior, and learning, you likely will see some of these areas get better, too. Given the chance and some help, children with CP can do more on their own.

Not every child with CP is the same. Some children have very tight

muscles while others have very loose muscles. Some children may have

very clumsy or jerky movements. CP may affect only one side of the body

(right or left) or one half of the body (top or bottom) or the whole body.

This book has some basic techniques that are good to use for all children

with CP and some that are helpful only for children with certain types of CP.

None of the techniques are bad or harmful, but a skilled occupational

therapy practitioner should guide you through the techniques and help you

choose what is best for each child. After you get training and experience,

we hope you will teach other caregivers of children with CP the same

knowledge and skills you learned from *How to Help a Child with Cerebral*

Palsy.

Section I:

Presentations of Cerebral Palsy

❖ Some children with cerebral palsy have very loose muscles. This is called **hypotonicity** or **low muscle tone.**

It is hard for the child to hold him or herself upright.

Because the child cannot hold his head up, he cannot see and explore his environment.

❖ Other children with cerebral palsy have very tight muscles. This is called **hypertonicity** or **spasticity** or **high muscle tone.**

Pushes head and neck backward

Keeps hands in fists and arms in toward body

Turns legs inward - it may be hard to move knees apart.

Very high muscle tone can cause deformities if the limb is not moved for a long time.

❖ One side of the child's body may be more affected than the other. This is called **hemiplegia**.

The child may have high muscle tone on one side.

This causes the child's trunk and hips to be unevenly aligned.

❖ Another type of cerebral palsy is called **athetosis**.

The child may turn his or her head and eyes away from the action. For example, if reaching with his left hand, the child may turn his head/eyes to the right.

The child may have low muscle tone in his or her trunk.

Muscle tone in the arms and legs changes between high and low tone.

❖ A child with cerebral palsy may have **ataxia**. The child with **ataxia** is clumsy when he or she is trying to move.

The child may not like to move because it is hard for him or her.

The child does not have good control over his or her movement. Larger motions are easier.

Has poor trunk stability and balance.
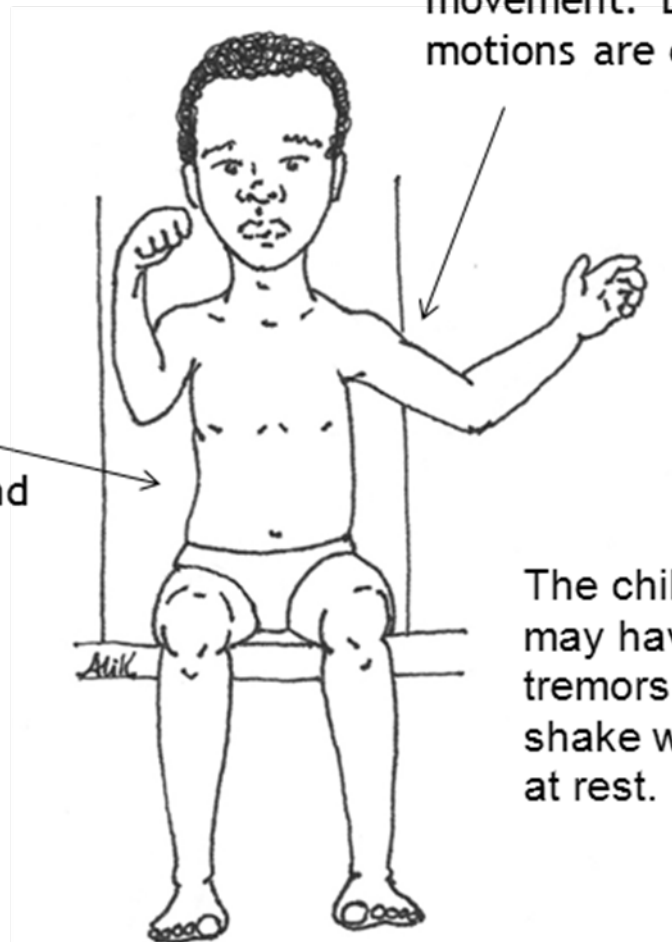
The child may have tremors or shake when at rest.

Section II:

Body Structures and Positioning

It is helpful to use <u>key points of control</u> when handling a child with cerebral palsy.

Key points of control are body structures from which you can influence posture and movement. The child is still able to actively move his or her outer limbs, such as the hands or feet.

Jaw

Shoulders

Trunk

Hips/pelvis

Knees

Ankles

Feet
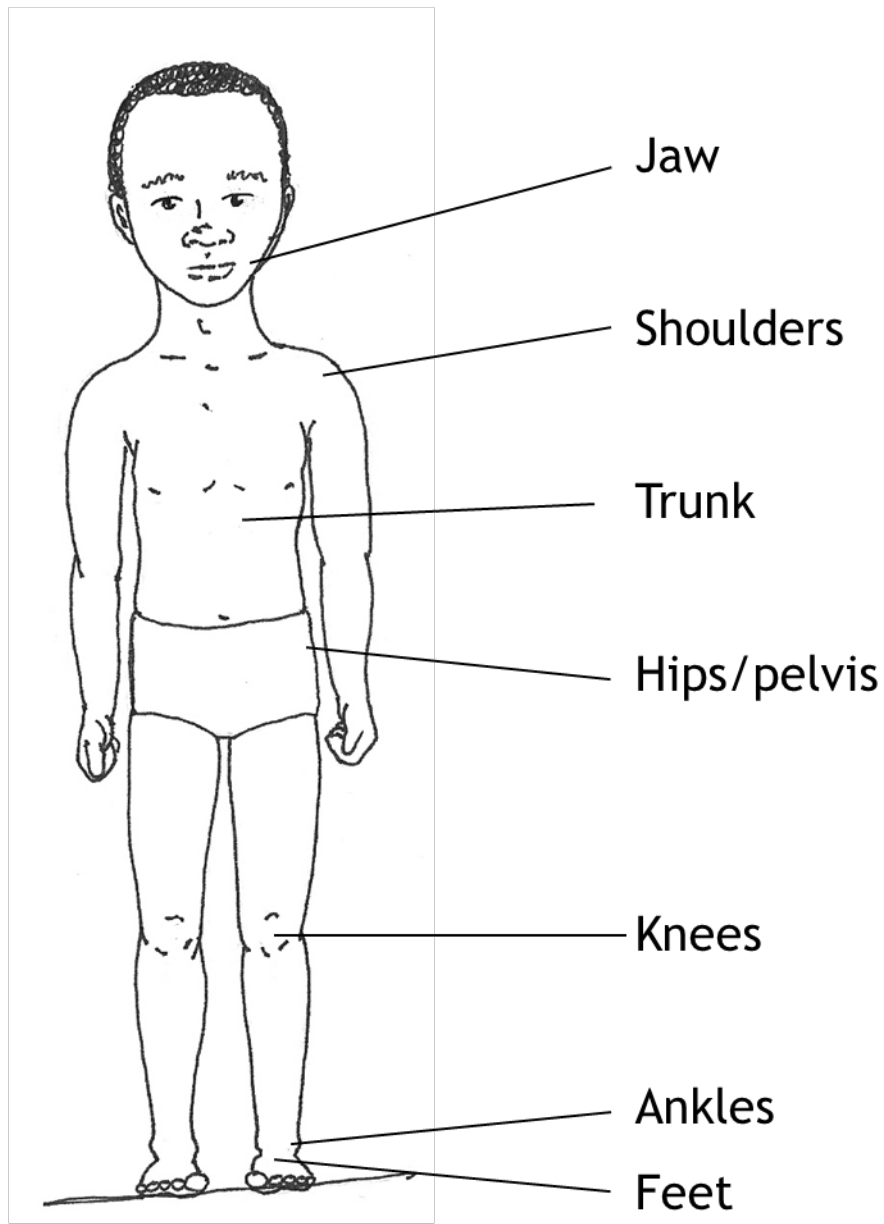
When positioning a child with cerebral palsy -

Head, shoulders, trunk, and hips in alignment

90° bend at hips, knees and ankles

Weight is balanced between two sides of the body
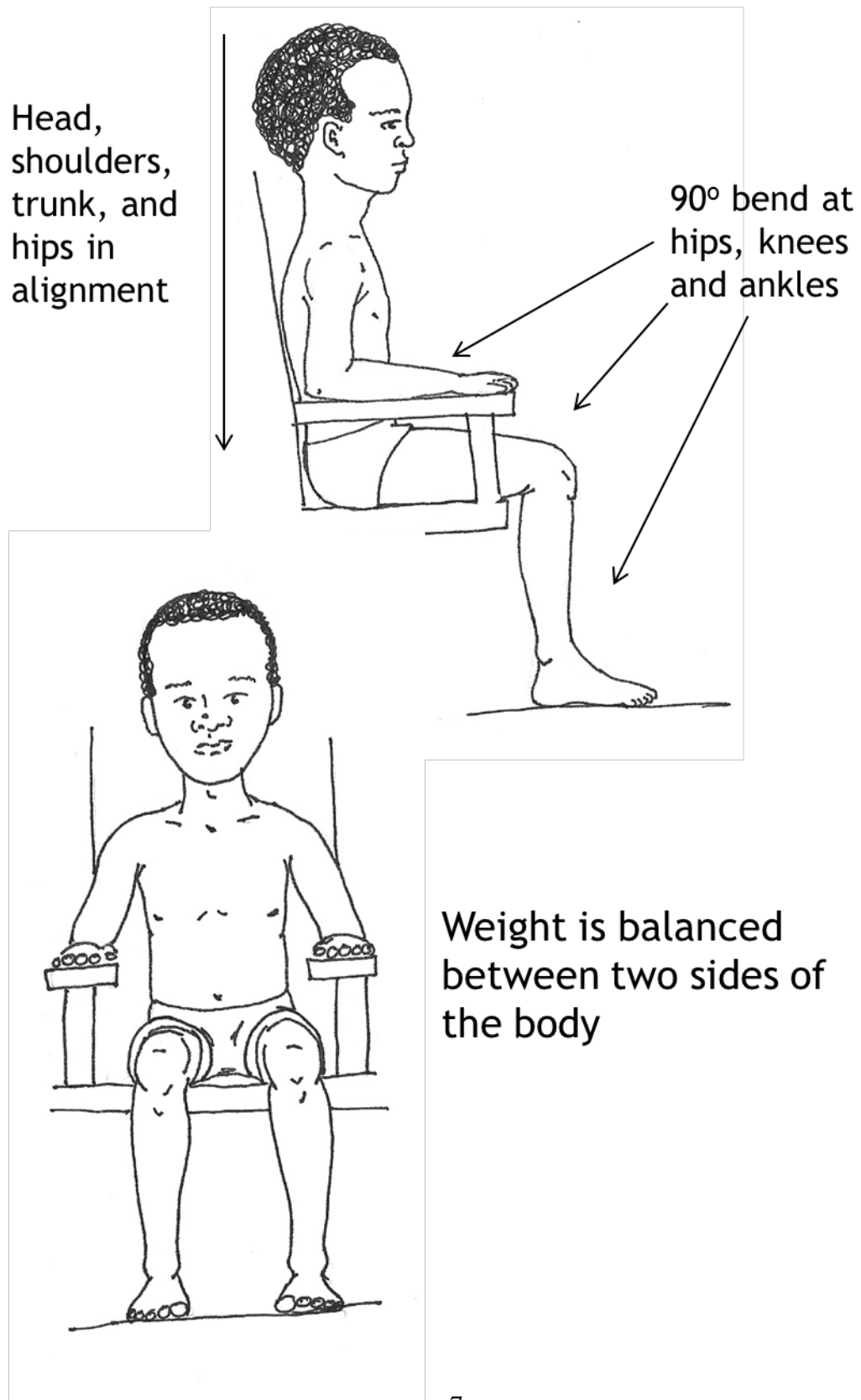
Proper positioning –

- Increases the child's access to the environment.

    o The child can access the environment through the things he or she touches or sees.   This is part of how children learn.

- Helps the child to feel safe and secure.

- Supports movement of the child's arms and hands.

- Improves breathing.

- Prevents and/or helps to correct deformity.

    o Very high muscle tone can create deformities in the child's limbs when left in one position for too long.

Use rolled up towels, pillows, and other materials to help properly position the child.

High back and/or head rest – To support trunk and head in alignment

Hand roll– To prevent deformity and skin breakdown
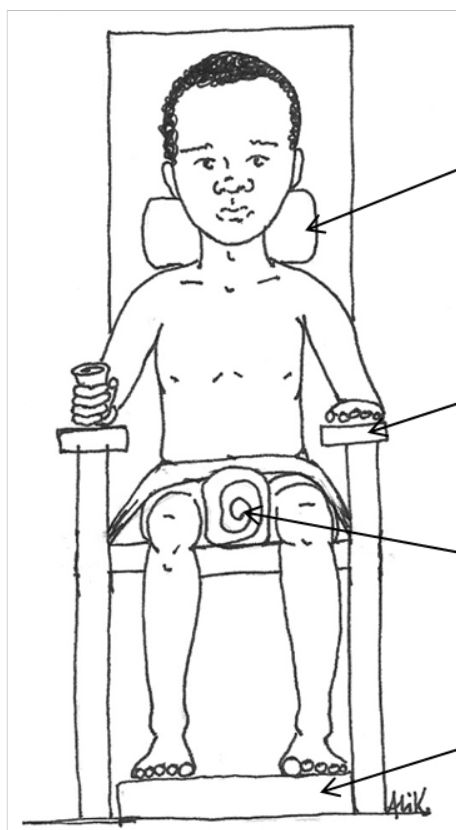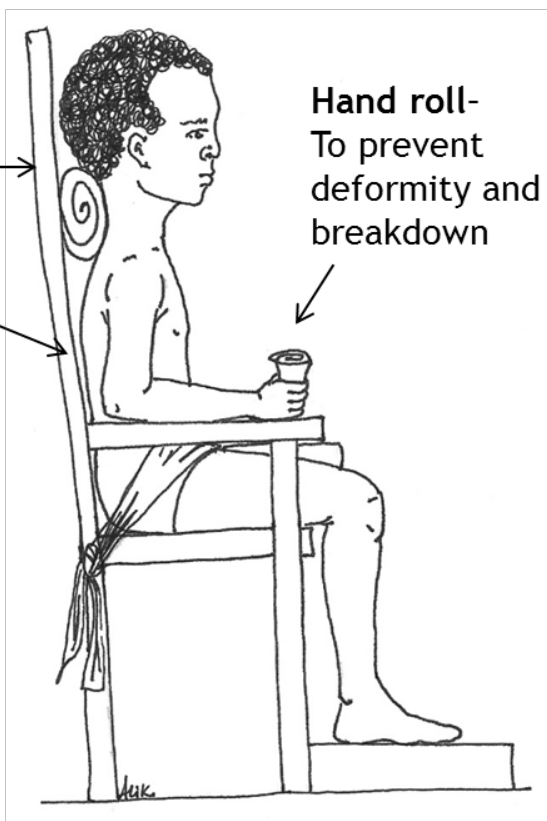
Neck roll – To keep child's head, neck, and shoulders aligned

Arm rests – To provide side support to trunk and position arms

Knee block – To keep knees evenly aligned

Foot stool – Allows child to rest feet flat on floor

Section III:

Self-Care

Functional Transfers and Mobility

When helping a child to sit up –

Hold the child's shoulders; bring shoulders in toward the body.

Support the child's shoulders and trunk to help him or her sit up.

Don't pull on child's arms.

This can cause the child to push his head/neck back, making it harder to sit up.

When helping an older or heavier child sit up –

1 – Help the child roll onto his or her side, to face the edge of the bed or mat.

2 – Bend child's legs both at hips and knees.
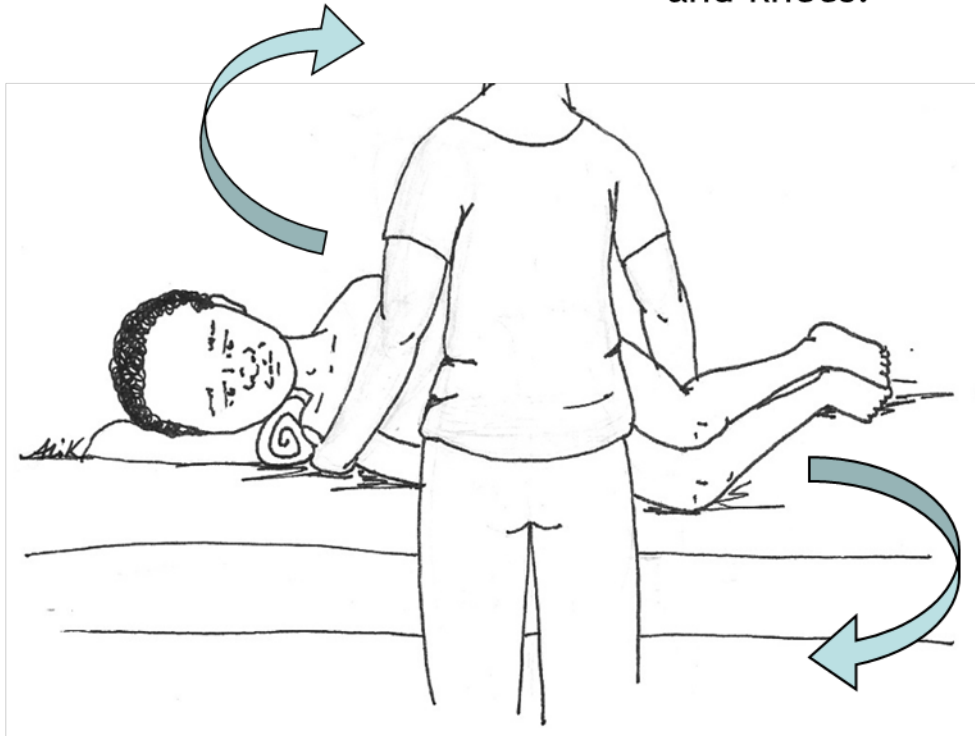
3 – At the same time:
- Lift the child's upper body, holding under the child's shoulder.
- Bring the child's legs over the edge of the bed or mat, pulling them toward your body.

Getting child into position to stand up –

After the child is sitting, help the child to move to the edge of the bed or mat.

Child is leaning forward, with head over knees.

Arms folded across chest

Sitting at the edge of the chair, bed, or other surface.

Feet flat on the floor or solid surface.

When lifting an older or heavier child –

Hold the child's trunk back against your body.
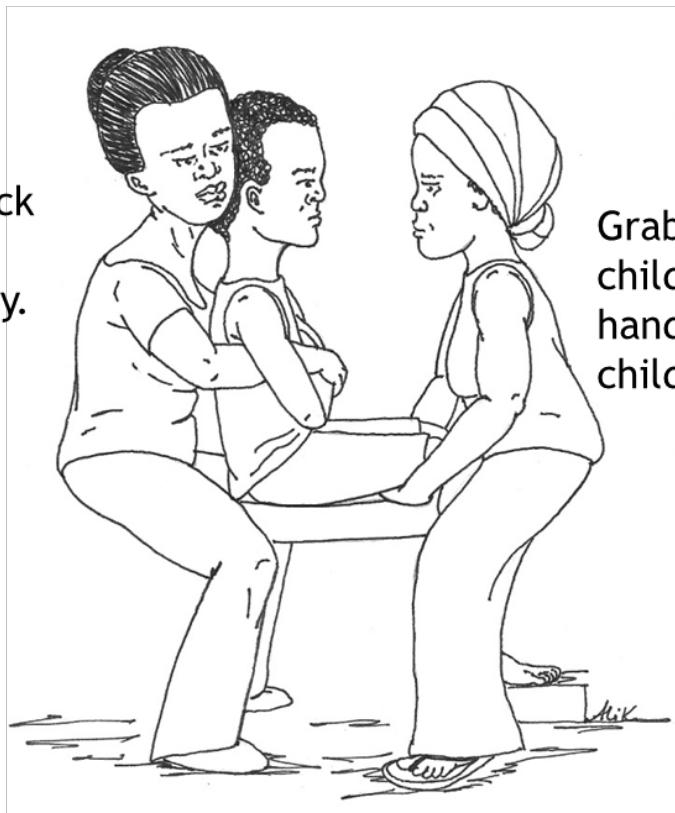
Grab under child's thighs, hands behind child's knees.

❖ Both people lift at the same time.
❖ Take steps to side while carrying child.
❖ Keep your back straight, bending your knees when raising or lowering the child.

To hold child's trunk and arms as shown above –

Bring your arms under the child's arms from behind.
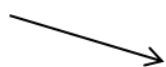
Fold the child's arms in front of his or her body, holding the child's forearms.

When carrying the child on your hip --

Use your arm to support the child's trunk against your own body.

Rest the child's legs over your hip, bending the child's hips slightly.
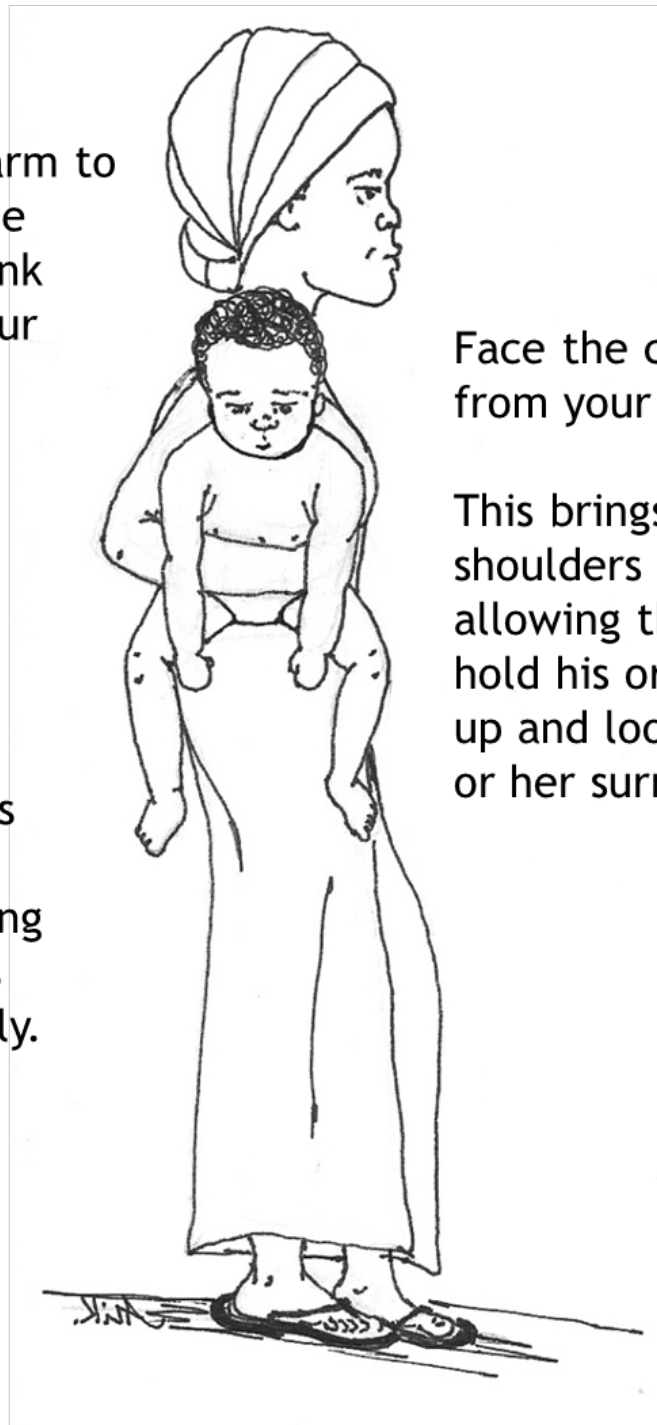
Face the child away from your body.

This brings the child's shoulders forward, allowing the child to hold his or her head up and look around his or her surroundings.

When carrying a child on your back --

Wrap the swaddle material over child's shoulders.

This keeps the child's head up and he or she is able to look around.
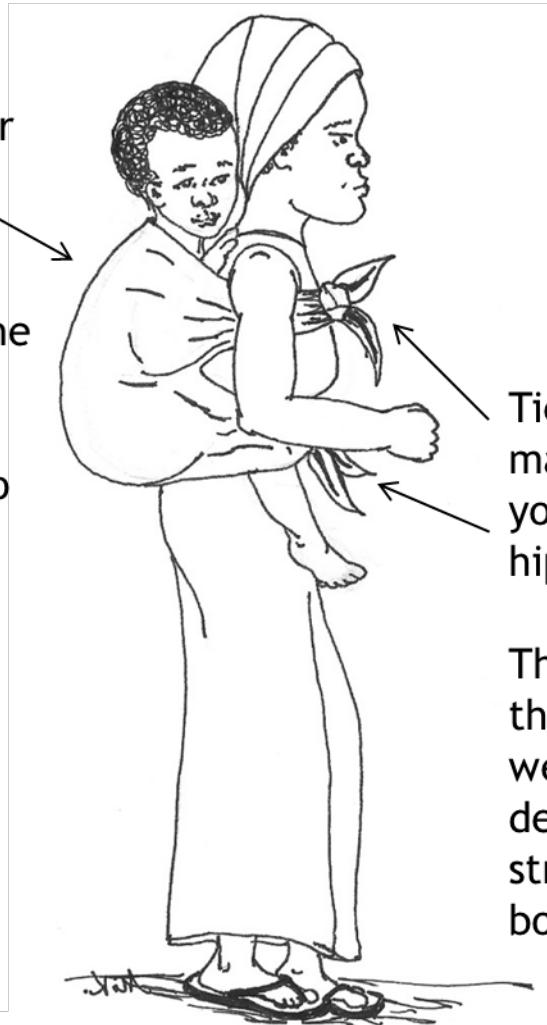
Tie the swaddle material across your chest and hips.

This spreads out the child's weight and decreases the stress on your body.
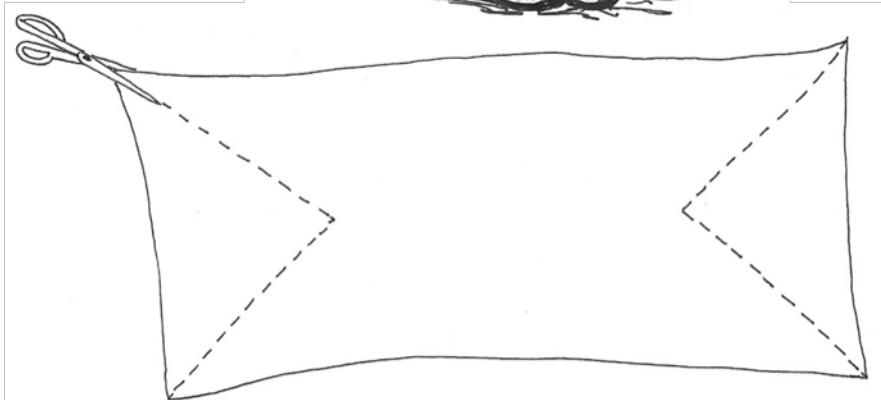
Use this design to cut material for swaddle, making two ties.

Dressing

When helping a younger child to dress –

A child with cerebral palsy may not be able to sit without holding him or herself up. This makes it hard for the child to do dressing tasks alone.

❖ One way to help a young child dress is to lay the child on his or her stomach across your lap.

Brings shoulders forward, making it easier to put arms through sleeves.

Hips and knees are easier to bend.
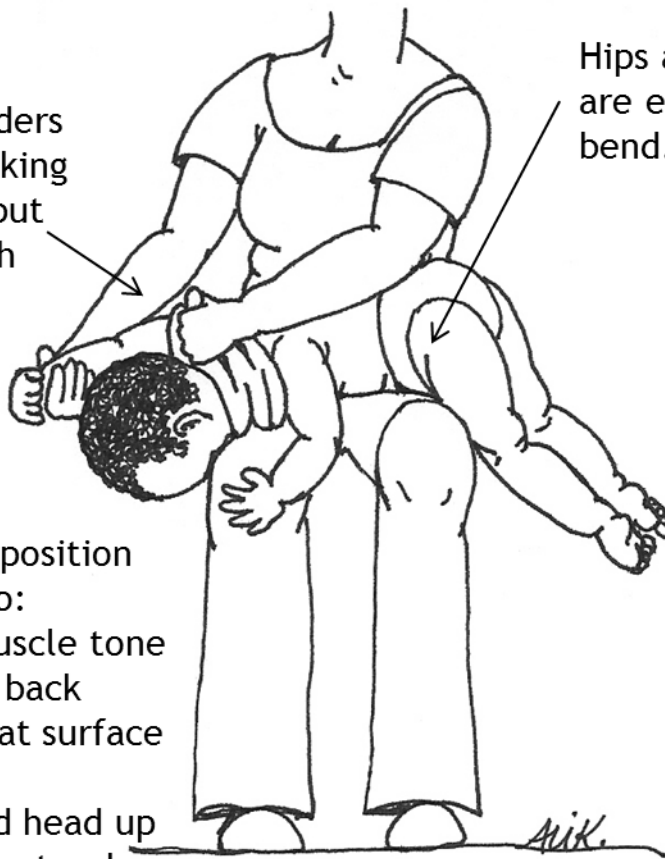
This is a good position for a child who:
- Has high muscle tone and pushes back against a flat surface
  OR
- Cannot hold head up and has poor trunk stability

When helping a younger child to dress -

❖ If the child can hold his or her head up, dress him or her while sitting on your lap or on the floor in front of you.

Bend the child's leg at the hip when lifting foot up to dress.

❖ Face the child away from you, supporting his trunk in an upright position.

❖ Tell the child what you are doing as you dress him or her. This helps the child learn the tasks.

❖ In this position, the child can watch the dressing tasks.

❖ If able, he or she can begin to help with dressing, doing parts of the tasks.

If the child has hemiplegia, dress his or her more affected side first.

When helping an older child to dress –
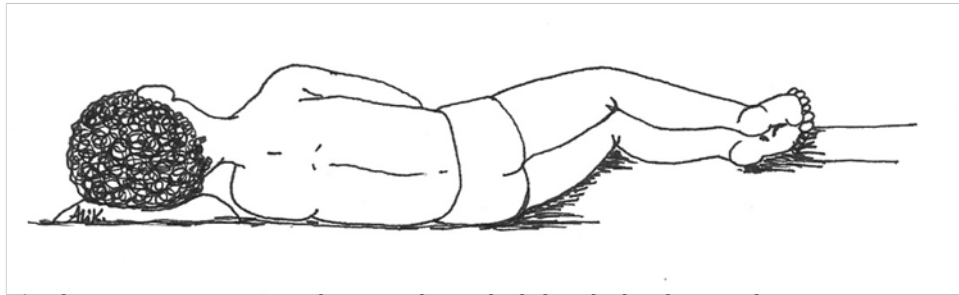
- ❖ It is easiest to dress the child while he is lying on his side.

- ❖ This position makes it easier for you to manage the child's arms and legs.

- ❖ It also allows child to help with dressing task if he or she is able to.

To prepare a child for dressing task -

Hold child's knees

Roll the child's whole body from side to side.
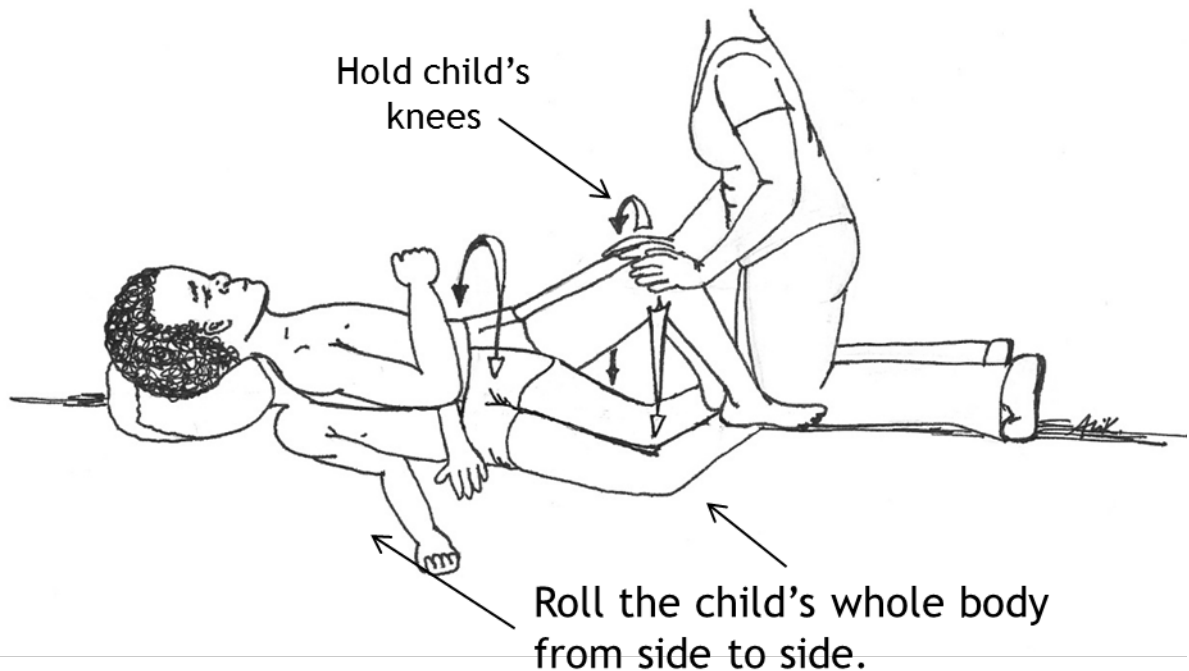
- ❖ Do this before and during dressing tasks.
- ❖ It helps to decrease muscle tightness

When helping an older child to dress –

With child lying on his or her side

❖ Lay child on a bed or mat at a height that:
- You can easily reach the child's limbs
- Does not put stress on your back

❖ Keep the child's clothes within easy reach

❖ Encourage the child to help dress him or herself

Child's shoulders come forward.

This makes it easier to put his arms through shirt sleeves.
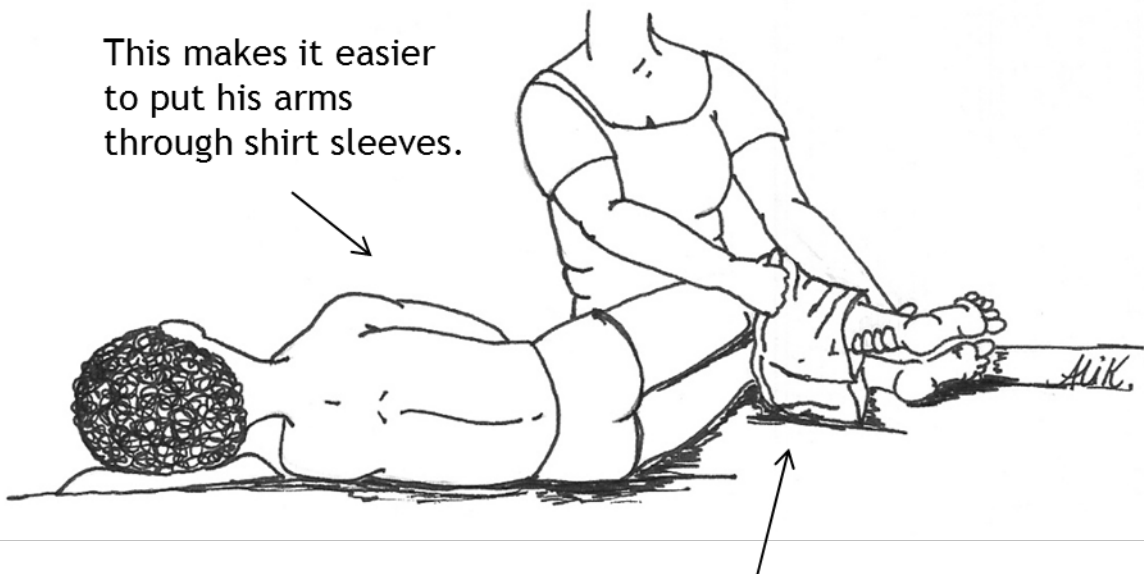
Lying on his side may decrease high muscle tone.

This makes it easier to bend the child's legs at the hip and knee to put pants on.

When a child begins to dress independently -
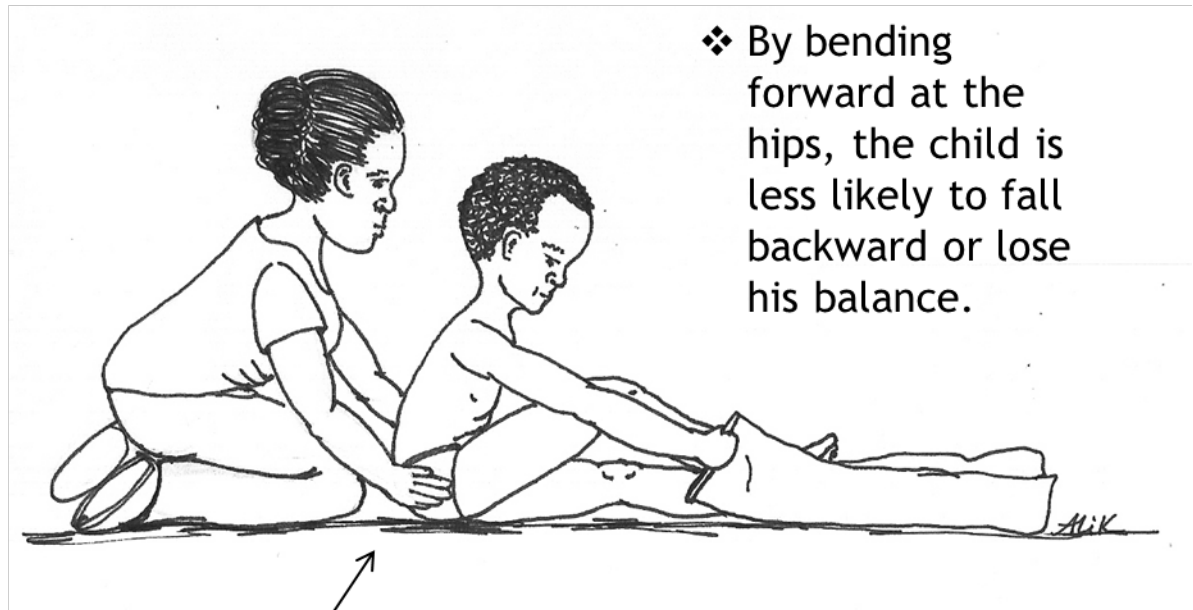
❖ By bending forward at the hips, the child is less likely to fall backward or lose his balance.

Hold child's hips to stabilize the trunk

❖ Help the child keep his balance while he is using both hands to complete dressing tasks.

❖ Provide only as much support as the child needs.
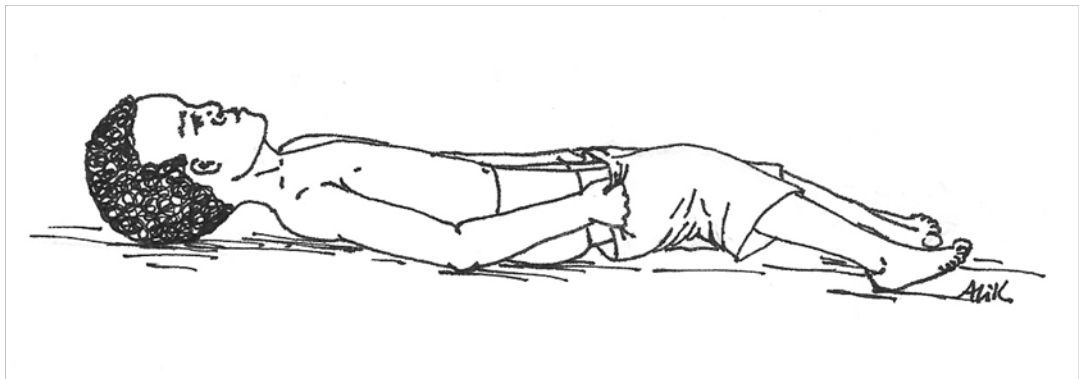
❖ The child may be able to complete dressing tasks independently while lying down on his or her back or side.

When a child begins to dress independently -
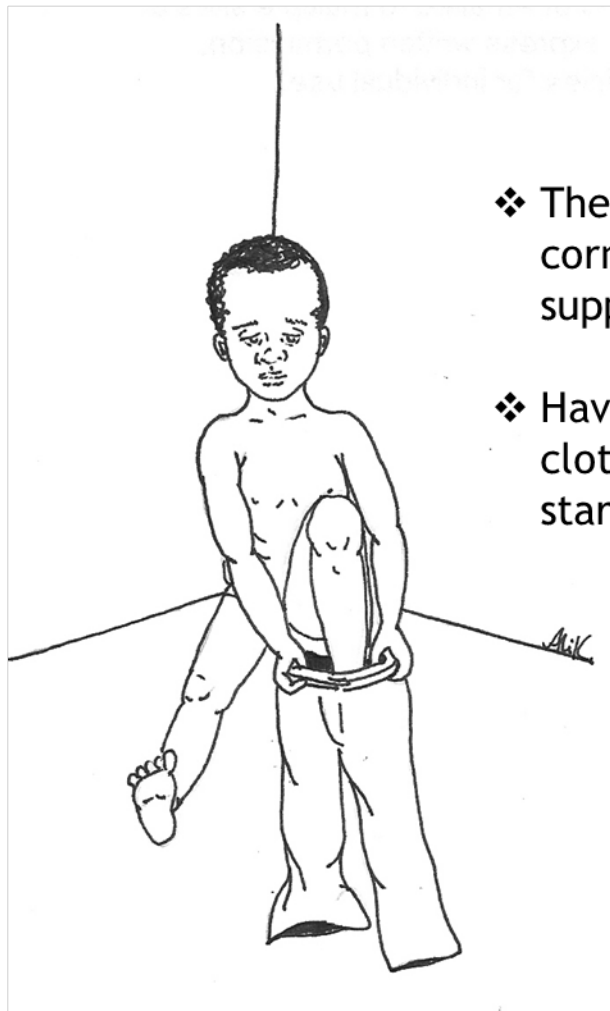
❖ The child may use the corner of the wall for support and balance.

❖ Have the child's clothing close by before starting dressing tasks.

❖ Make dressing tasks part of the child's daily routine.

- Do dressing tasks in the same order.
- Get dressed in the same place each day.
- Give the child directions and cues to do tasks in the same way each time.

When a child begins to dress independently -

❖ The child may also dress him or herself while seated in a chair.

❖ If the child's trunk is stable and supported, it allows the outer limbs to move more easily.
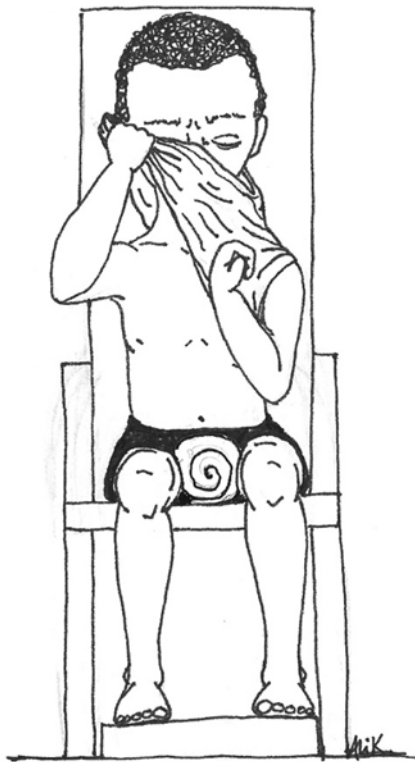
Adapted way to put on shirt for a child with hemiplegia:

1. Put the child's more affected arm through the shirt sleeve.
2. Pull sleeve above the elbow.
3. Pull shirt over head.
4. Put opposite arm into opposite sleeve.

Feeding

When preparing the child for feeding –

❖The child may not have good control over the muscles of his or her mouth and jaw.

❖You can use different techniques to help the child get ready to eat.

For the child who has tight muscles in the cheeks and mouth

Use your whole hand to apply firm pressure over the child's cheeks and lips.

The pressure helps to decrease tightness in the muscles.

Stroke your hand in a downward motion.

For a child with loose
muscles in his cheeks
and mouth
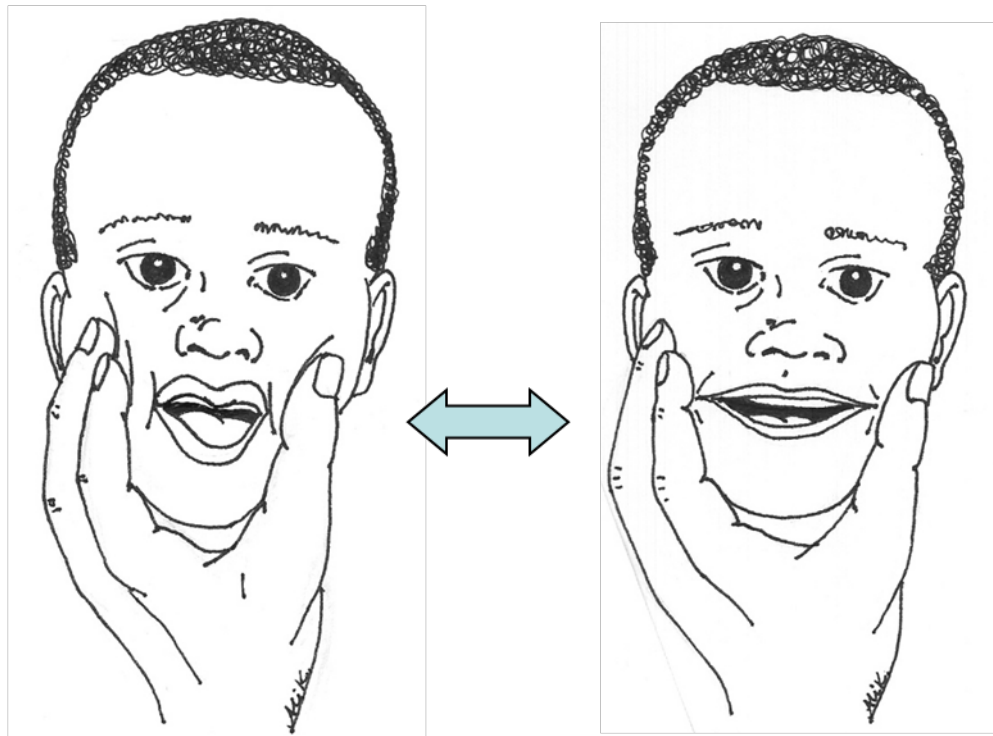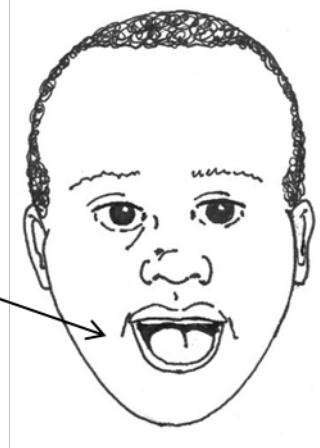
❖ Place thumb and fingers on sides of the
child's mouth.

❖ Apply a **quick stretch** to the child's cheeks
and lips.

❖ Repeat stretch several times before feeding
to increase muscle tone and strength in
facial muscles.

For a child with loose muscles in his cheeks and mouth
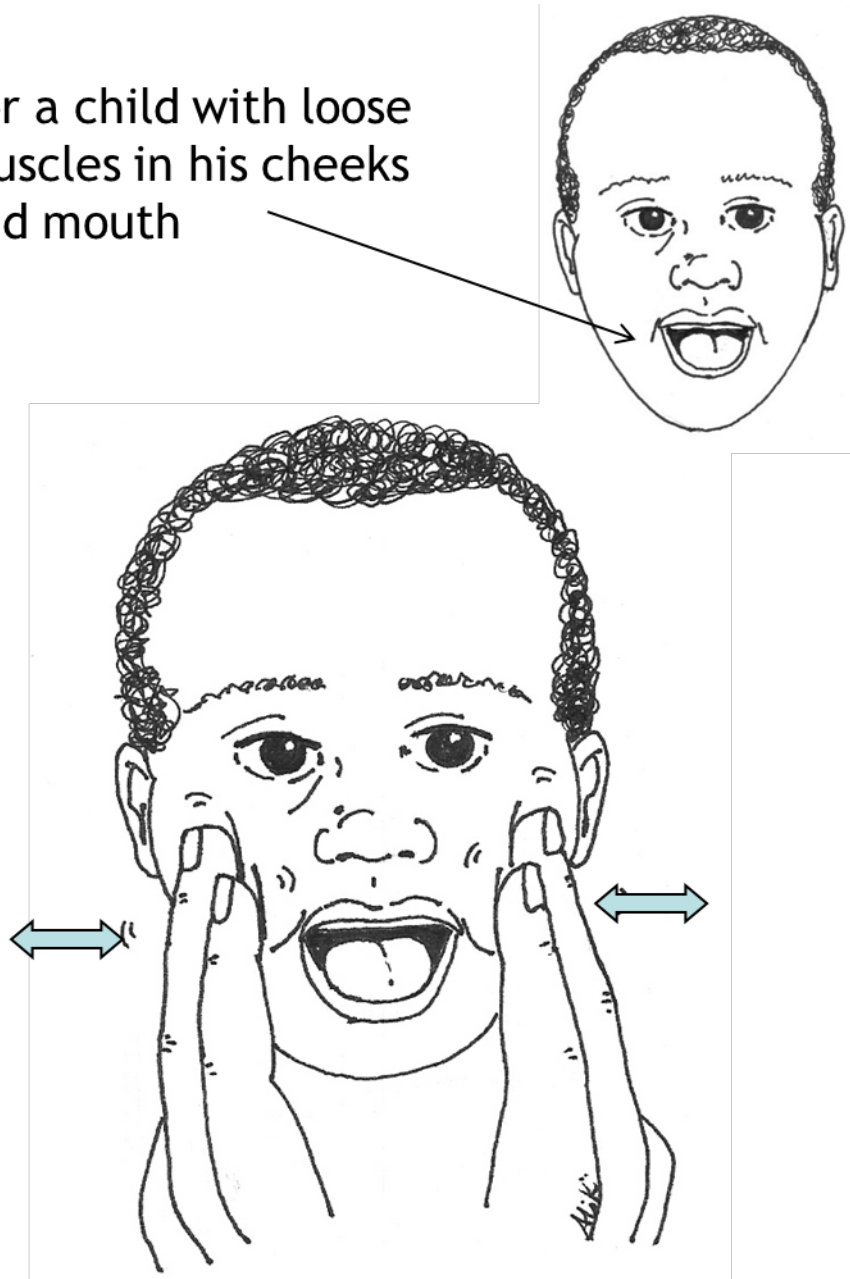
❖ Place two fingers on each of the child's cheeks.

❖ Quickly **tap** child's cheeks.

❖ Quick tapping will increase muscle tone in cheeks and lips to prepare child for feeding.

When feeding the child –

❖ The child may still need you to support his or her jaw during feeding.

❖ If feeding the child from the side, use the technique shown below.

May place your thumb along child's cheek to provide extra jaw support.
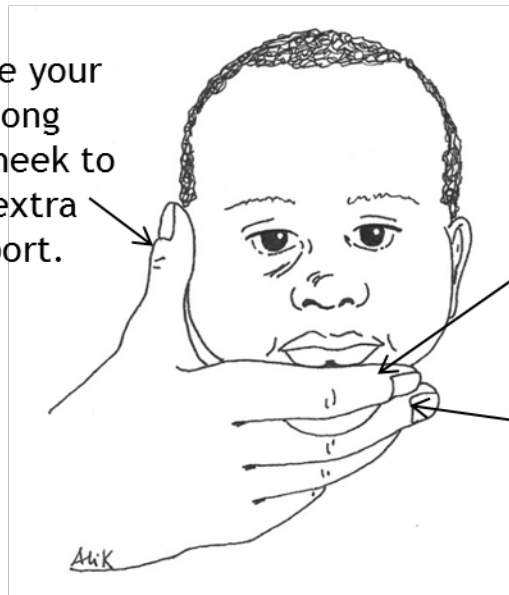
Put your first finger over child's chin, below the bottom lip.

Put your middle finger under child's chin.

Bring spoon to child's mouth below child's eye level.

This keeps the child from pushing his head back.

Only provide as much support to jaw as the child needs.

❖ Keep your hand on the child's jaw during the whole feeding. Do NOT move your hand away between each bite of food.

❖ If feeding the child when sitting in front of him or her, use the technique shown below.

Place fingers on child's cheek, along jaw line.

Place thumb on child's chin.

❖ Use your thumb to support the child's jaw during feeding.

❖ Keep the mouth from opening too quickly or too much.

❖ Keep your hand on the child's jaw during the whole feeding. Do NOT move your hand away between each bite of food.

Other things to think about when feeding the child:

❖ Proper positioning is very important.
  • The child's head, neck, and trunk should be aligned.
  • It may help for the child to tuck his or her chin down while swallowing.
❖ Pay attention to how quickly you are feeding the child. He or she may need extra time.
❖ Do NOT put too much food on the spoon
❖ Put the food on the end of the spoon because it is easier for the child to take.
❖ The child may not like foods that feel a certain way.
❖ Do NOT use a spoon that is too big for the child's mouth or that will scrape the sides or top of the child's mouth.

❖ The child may have a **tongue thrust** reflex. This is when the child pushes his or her tongue out of the mouth.

Tilt the child's head forward a little bit. **Tongue thrust** happens when the child pushes his or her head back.

Stop the child from sticking out his tongue by pressing the bottom of the spoon onto the front of the tongue.

❖ The child may have a **bite reflex**. This is when the child bites down and does not open his or her mouth.
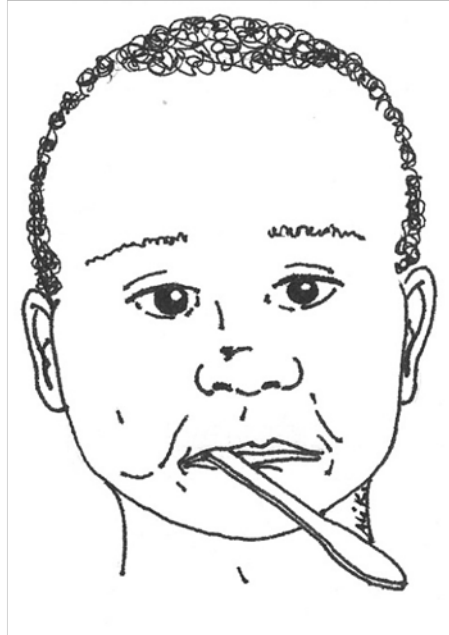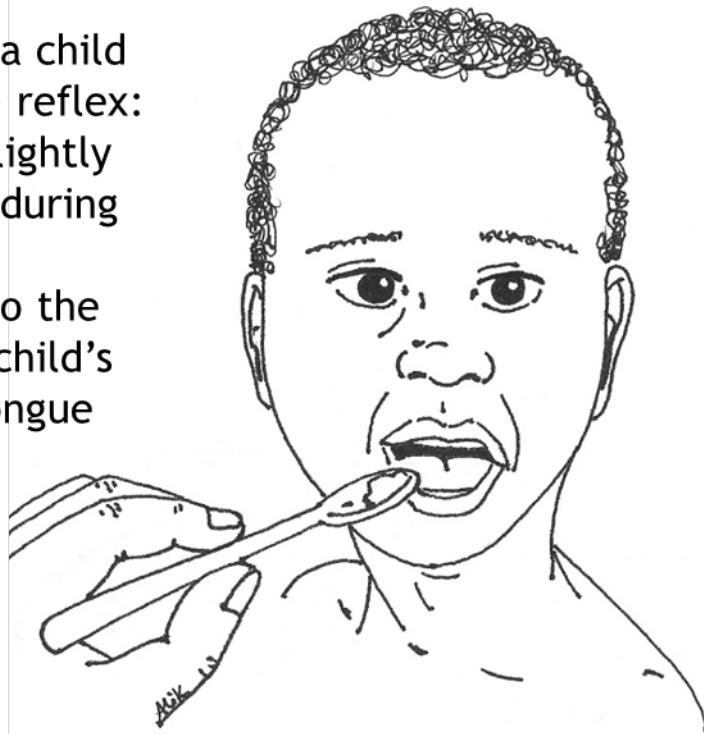

Do NOT forcefully remove the utensil from the child's mouth.

DO slowly turn the child's head or body to one side to get the child to let go.

When feeding a child who has a bite reflex:
• Turn head slightly to one side during feeding
• Bring food to the side of the child's mouth or tongue
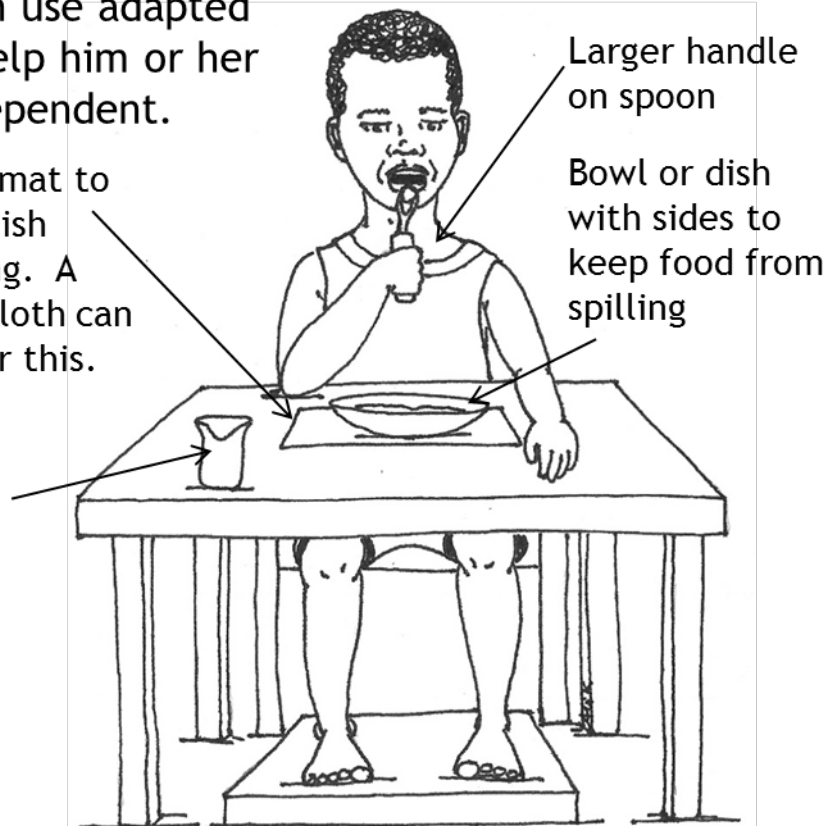
❖ When the child is feeding him or herself independently –

The child can rest his or her elbow on the table to stabilize the arm before moving the hand.

First, make sure the child is in a supported and stable position.

The child can use adapted utensils to help him or her be more independent.

Larger handle on spoon

Bowl or dish with sides to keep food from spilling

A non-slip mat to keep the dish from sliding. A wet washcloth can be used for this.

# Adapted Feeding Utensils

Cut-out for the nose
- Child can drink without tilting his or her head back
- By keeping neck slightly bent forward, it is easier for the child to swallow.

Flared edges of the cup fit more to the child's lips.

Use spoons with a **shallow bowl**. It is easier for the child to take food from.
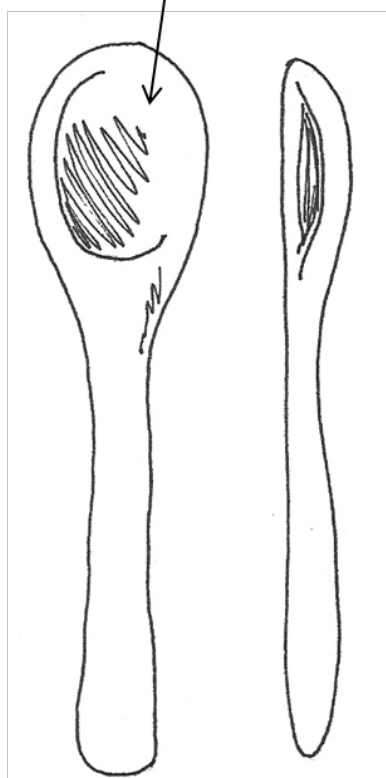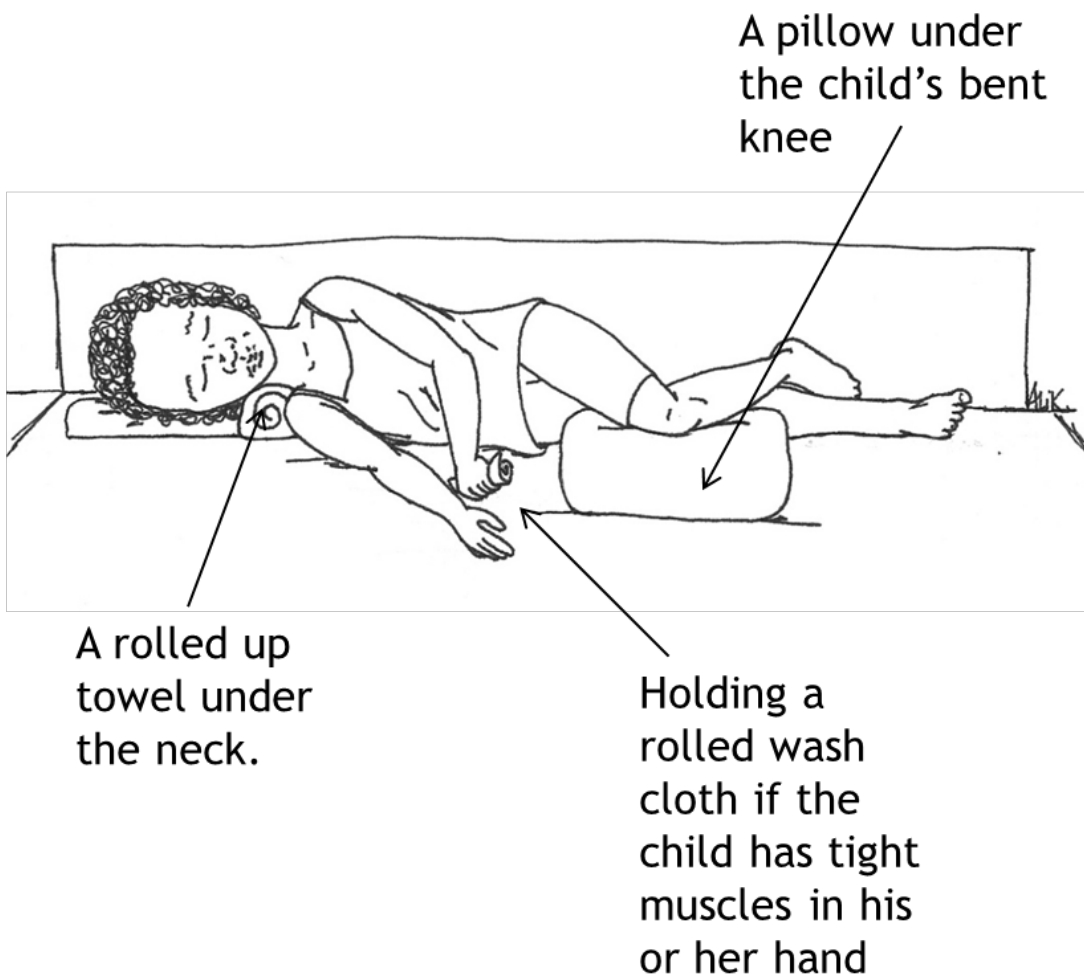
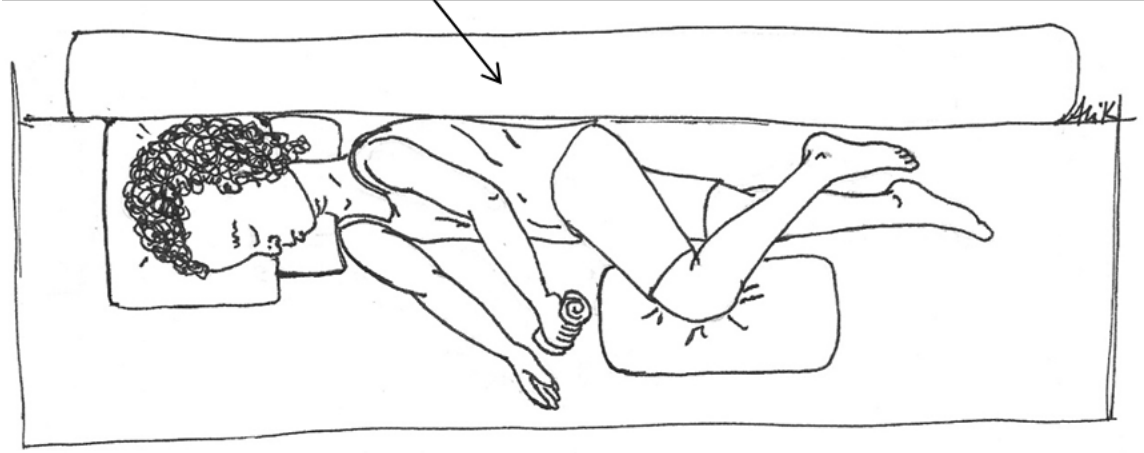**Built-up or larger handles** on utensils make it easier for the child to grasp and use the utensil.
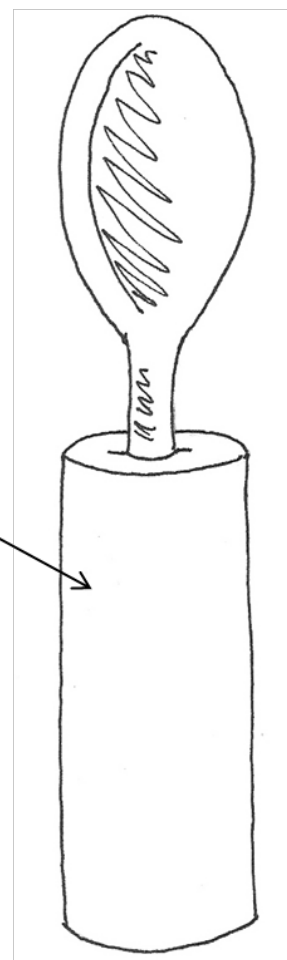
Sleep

❖ It is best for the child to sleep lying on his or her side.

❖ Use pillows, towels, or other materials to help keep the child's head, shoulders, trunk, and hips in alignment –

A pillow under the child's bent knee

A rolled up towel under the neck.

Holding a rolled wash cloth if the child has tight muscles in his or her hand

Use pillows or a solid surface to support child's back, keeping him or her from rolling back.

❖ Change the side the child sleeps on each night – left side one night, right side the next

❖ When the child is able to roll to position him or herself without help, he or she may find a more comfortable way to sleep.
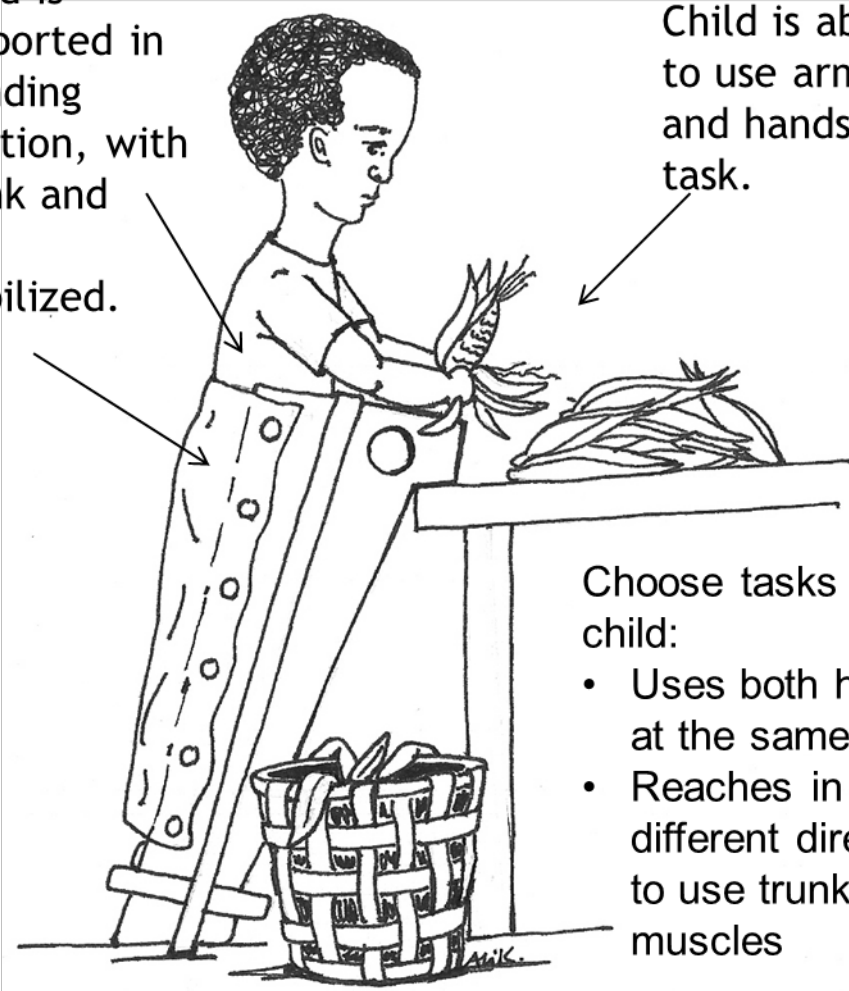
Section IV:

Productivity

Housework

If the child is unable to stand on his or her own, you may use a **standing frame**.

Child is supported in standing position, with trunk and hips stabilized.

Child is able to use arms and hands for task.

Choose tasks that the child:
- Uses both hands at the same time
- Reaches in different directions to use trunk muscles

It is important for the child to spend time standing because:
- It helps make the child's bones and muscles in his or her legs and trunk stronger.
- It takes pressure off the child's back or side from sitting or lying down.

Doing tasks in which the child bears weight on all four limbs can help to normalize muscle tone.
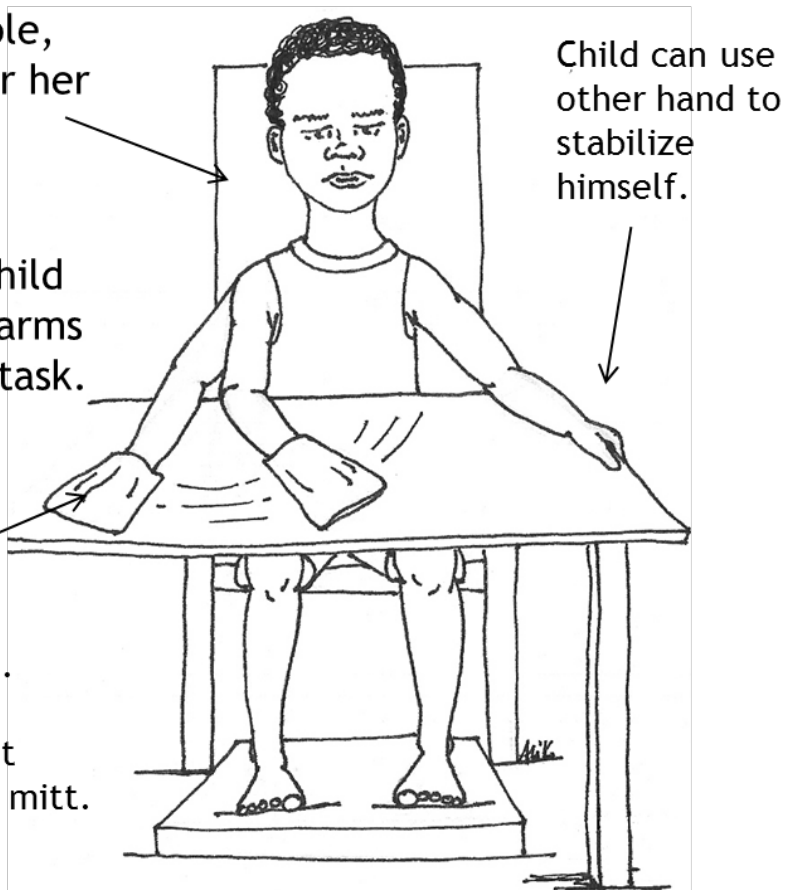
Change hands throughout task.

Child bears weight on knees, hips, shoulders, and elbows.

When having child do tasks at table, first put him or her in a supported position.

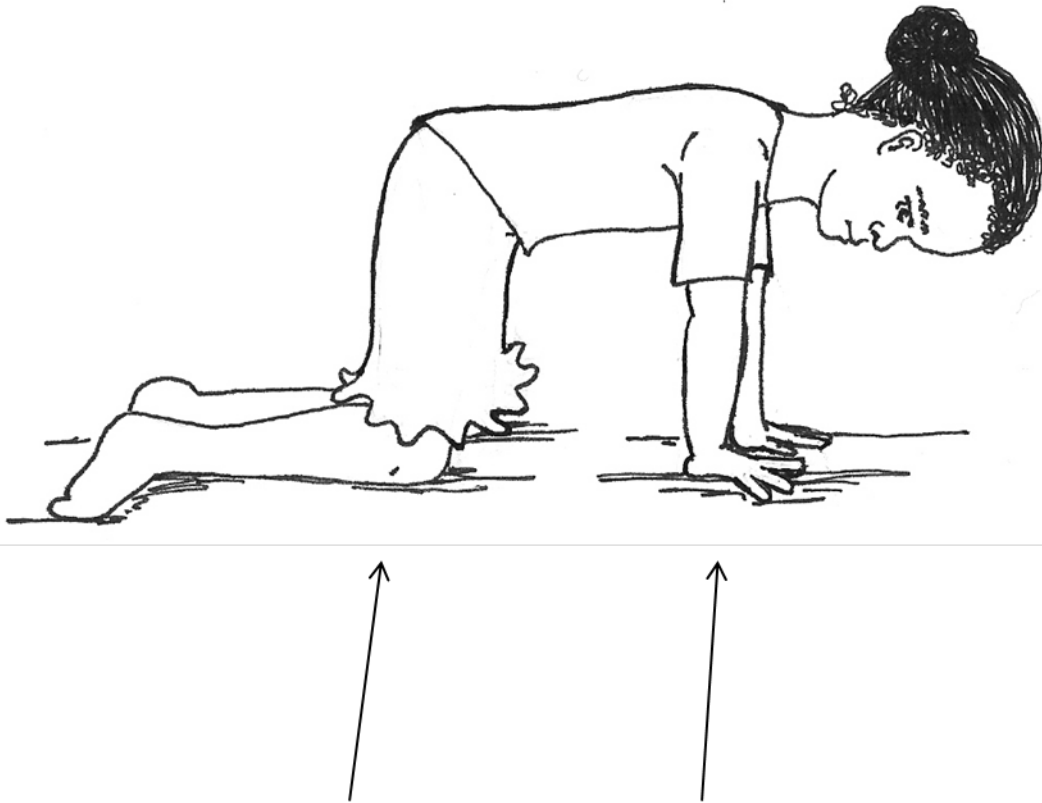This lets the child use his or her arms and hands for task.

Child can use other hand to stabilize himself.

Use a hand mitt instead of a cloth.

The child does not have to grasp the mitt.

School

Getting ready for school activities –

Normalize muscle tone by having the child bear weight on hands and knees.

*Normalize = high muscle tone decreases
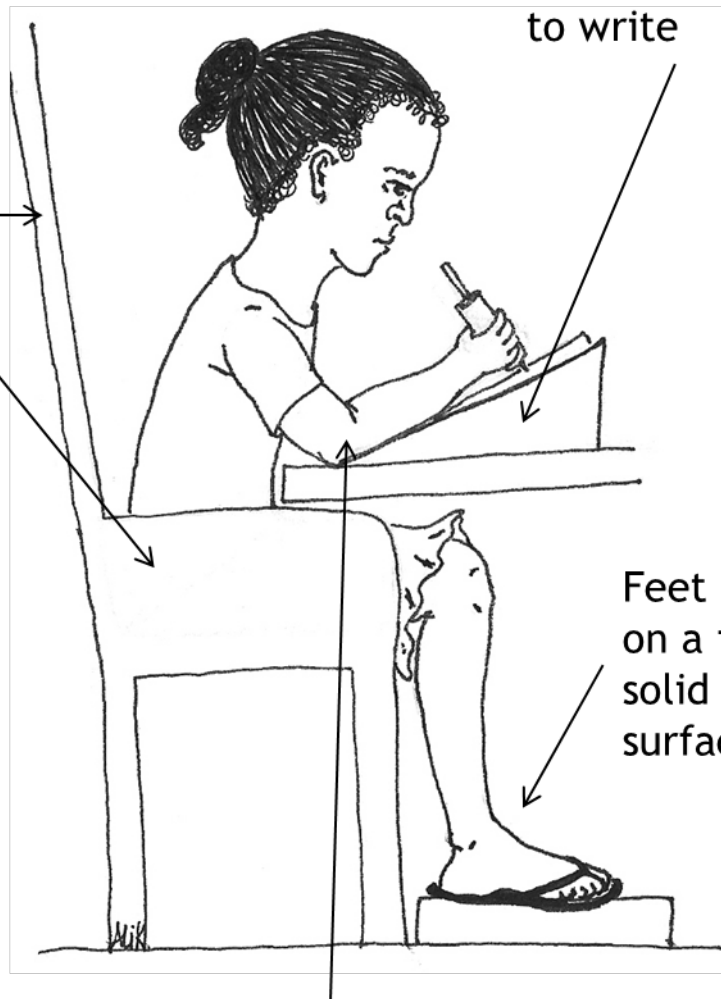OR
low muscle tone increases

This prepares the child to take part in school tasks.

When child is doing schoolwork –

First put the child in a supported, stable position.

An incline helps the child to extend or bring her wrist back to be able to write

A chair with a high back rest and arm rests stabilizes the child's hips and trunk.
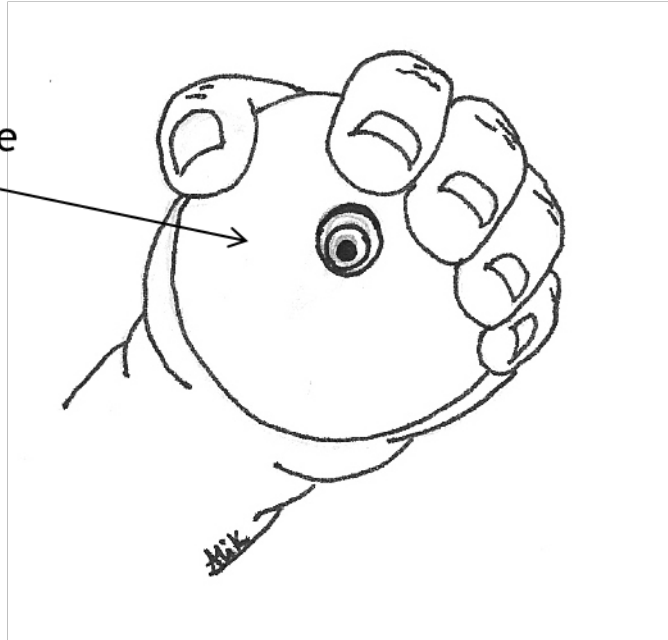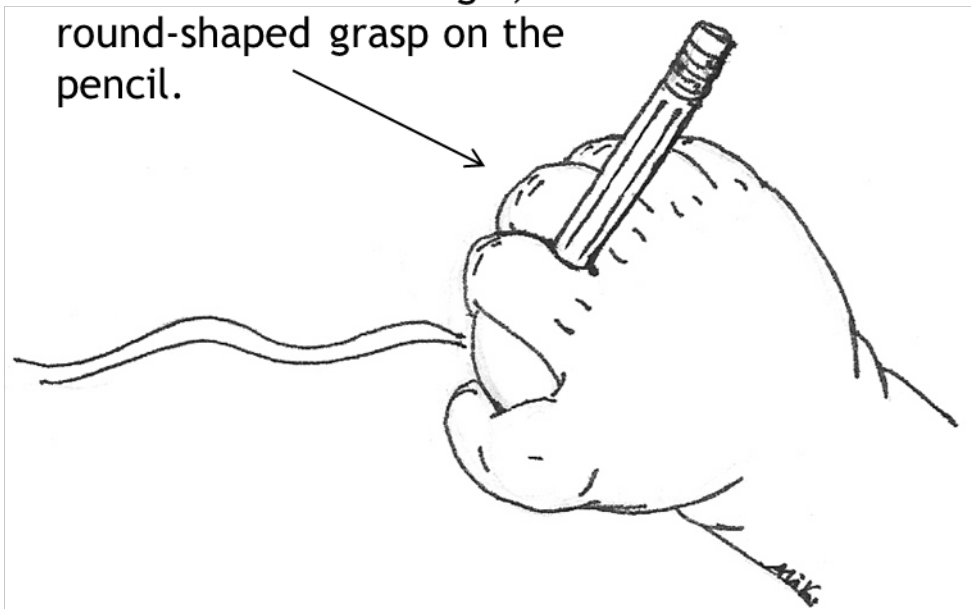
Feet resting on a flat, solid surface

By resting her elbow on the table, her arm and shoulder are stabilized. This allows more controlled hand function.

Children with cerebral palsy may lack the hand function needed to use a pencil.

Build up the grip around the pencil.

This built-up grip allows the child to use a larger, round-shaped grasp on the pencil.

Make an adapted writing tool -
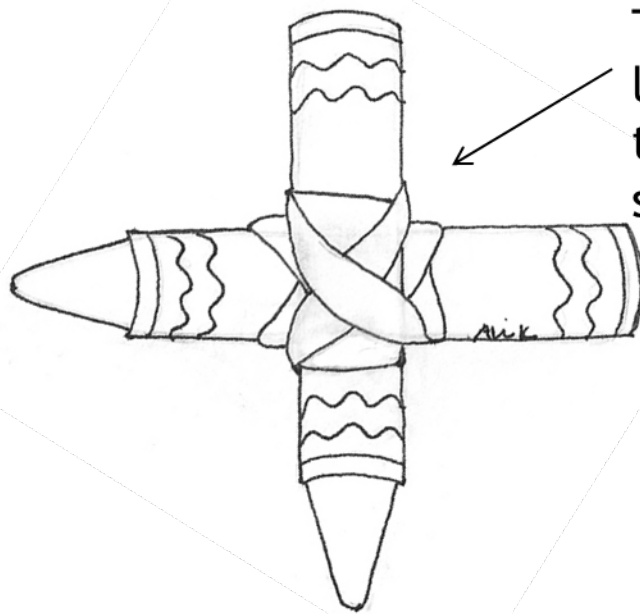
Tie or tape two large crayons together in a cross shape.

This writing tool can be grasped in several ways. It can be used by children with different levels of hand function.
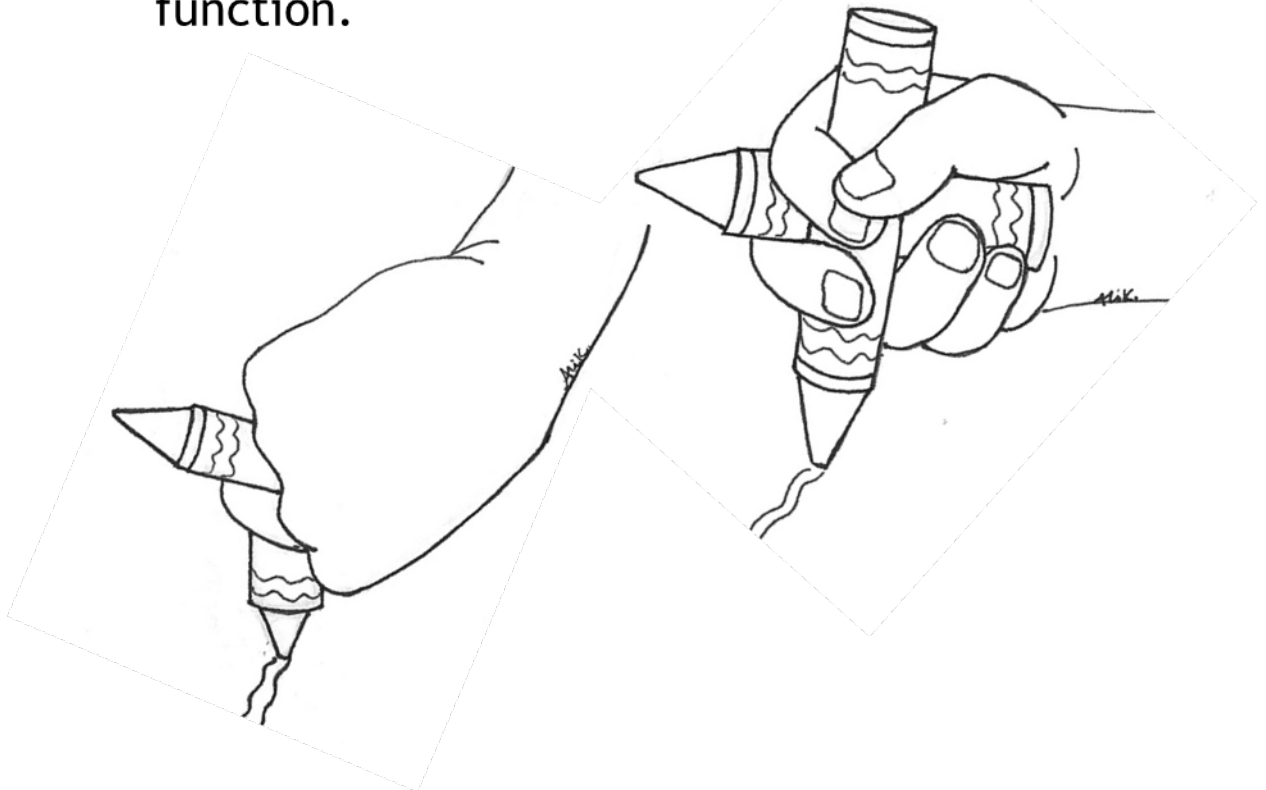
When child is doing schoolwork –

Set books in upright position to be in the child's line of vision.

Tie material across child's hips to keep the child from sliding forward .
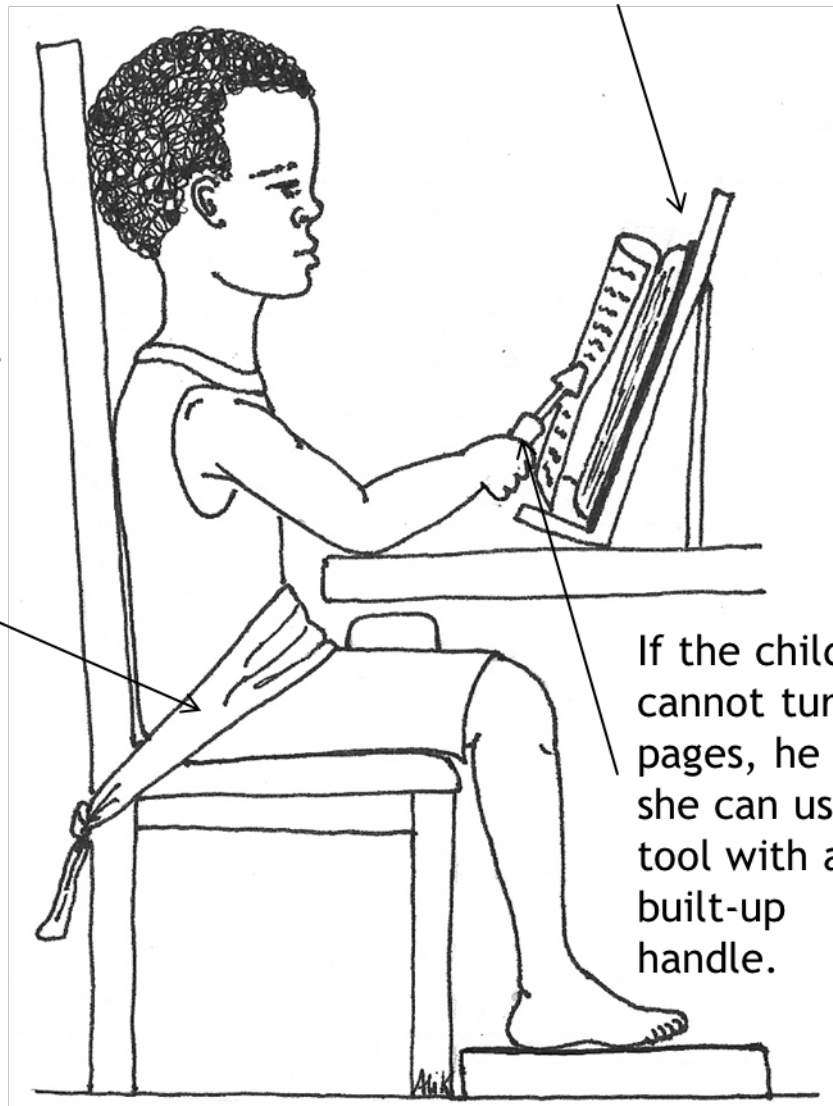
If the child cannot turn pages, he or she can use a tool with a built-up handle.

Play

When child is playing –

❖ Playing is one way the child learns. It lets the child explore the environment.

❖ Support the child in sitting position while he or she is using hands and arms to play.

Place your hands on child's shoulders or trunk.
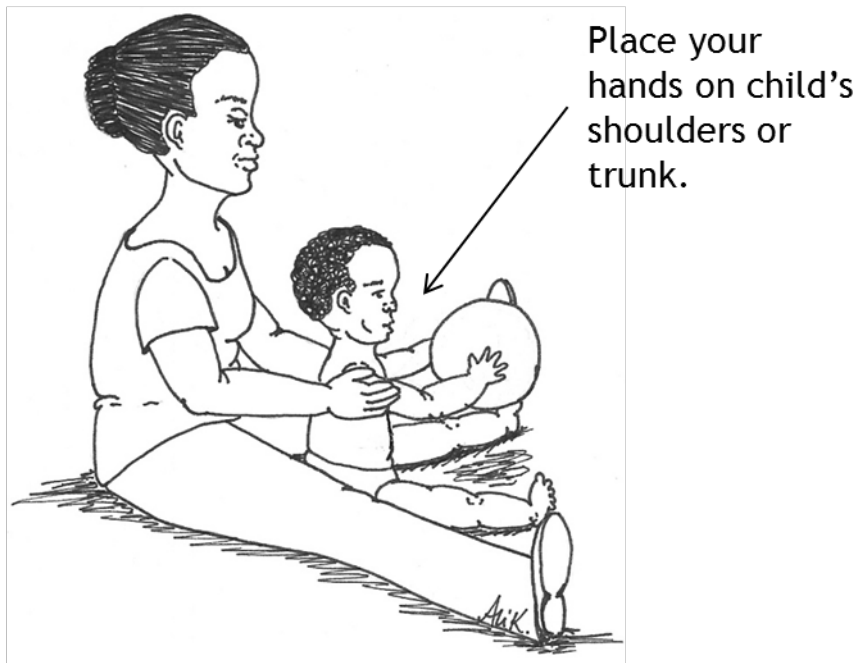
❖ Use a C-shaped pillow to support the child while he or she is lying on the back.

Head is supported off floor.

The pillow brings the shoulders forward, letting the child use both hands to play.
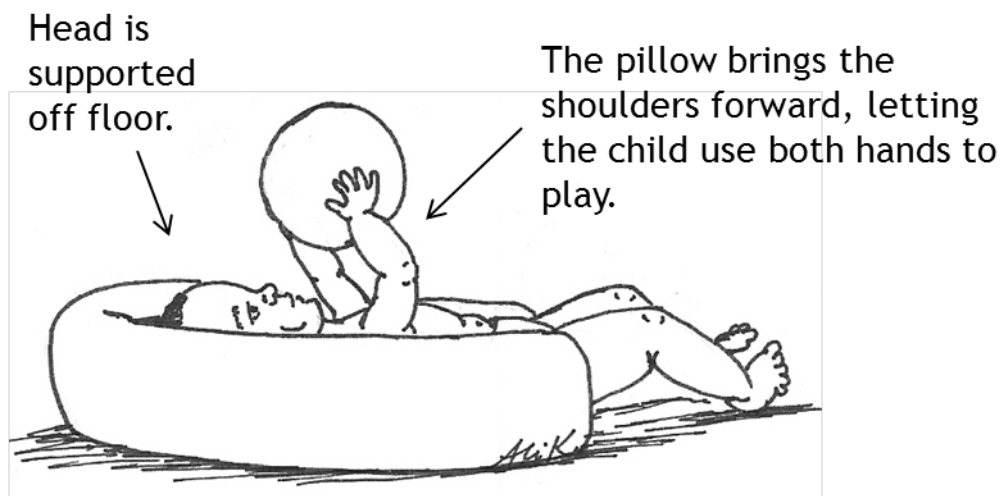
❖ There are many ways to put the child in a supported position for play.

In a simple chair

Use positioning devices, such as

•Lap belt
•Knee block
•Foot stool

to help support the child.

A corner chair supports the child's trunk and shoulders.

The child can also sit in corner of walls or furniture for support.

❖ The child may also play while supported, lying on his or her stomach.

Use an inclined board or mat to support the child.
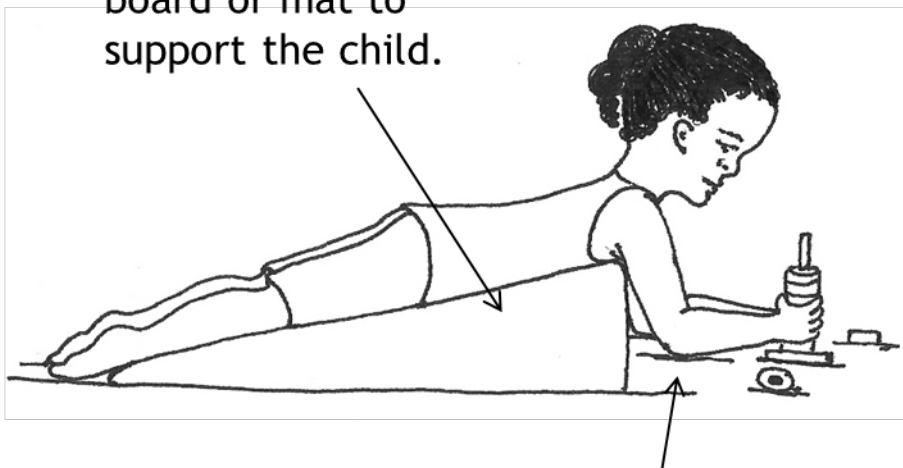
The child bears weight on his or her elbows.

Brings shoulders inward. The child can use both hands to play.
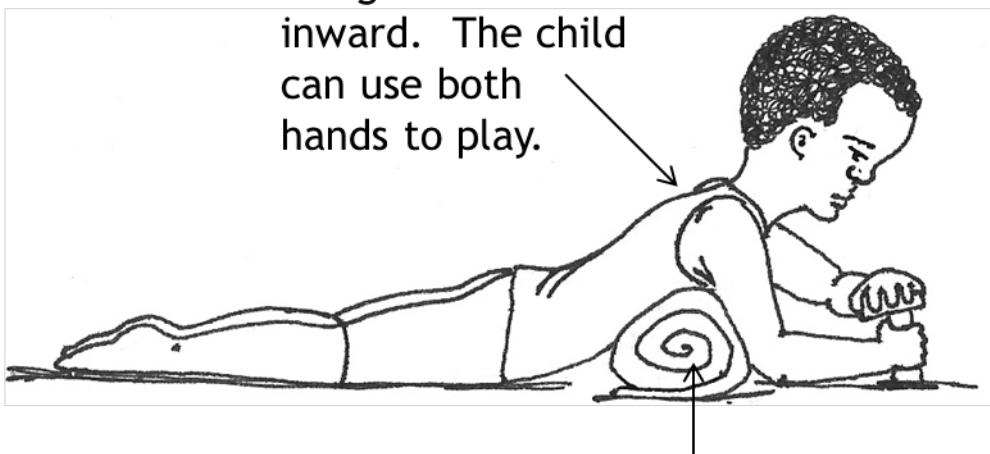
You can use a rolled up towel or pillow to support the child's upper body.

Appendices

Appendix A:
How to Make a Chair

How to Make a Chair from Recycled Cardboard and Paper was reprinted with permission from Jean Westmacott, People Potential (April 9, 2012).

Appendix B:
Resource List

Resources

Assistive cardboard equipment:

- Adaptive Design Association, Inc.

  Creative Constructions by M. Campbell and A. Truesdell (2000)

  email: adaptivedesign@aol.com

- Paper Furniture Enterprise

  http://www.paperfurnitureenterprise.com/worldwide.html

- People Potential

  http://www.peopleptential.org.uk

Nongovernmental organizations that support people with cerebral palsy:

- Cerebral Palsy Africa

  http://www.cerebralpalsyafrica.org/Ghana.htm

- Ghana Federation of the Disabled

  www.gfdgh.org/disability law.html

- Voluntary Service Overseas (VSO)

  http://www.vso.org.uk/about/where-we-work/ghana.asp

Reading and video list:

- Refer to bibliography in this document

Bibliography

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CHAPTER V

SUMMARY

Through this scholarly project, an occupational therapy-based (OT) educational

manual was developed to provide Ghanaian caregivers with basic information regarding

the care of individuals with cerebral palsy (CP). Development of the manual came after a

review of literature and personal communication with individuals in Ghana revealed the

need for increased training and education for informal caregivers of individuals with CP.

It is anticipated that through use of the manual, caregivers will be enabled in their ability

to carry out the role of caregiver, in turn improving the occupational performance of

individuals with CP and allowing this population to engage in meaningful occupations.

Several characteristics of the created educational manual make it a strong clinical

practice tool. First, an intentional effort was made to consider the culture of individuals

in Ghana, ensuring that the information included in the manual would be applicable to the

target population. In addition, the manual is both occupation- and theory-based. The

authors used occupational behavior models, frames of reference, and adult education

theories to guide them throughout completion of this scholarly project and creation of the

product. Lastly, this product was created through collaboration with persons with a

variety of skill sets. For instance, the advisor for this scholarly project has a great deal of

experience working with children with CP. Another faculty member has the role of

organizing the University of North Dakota's (UND) international service learning course

and has provided input throughout the process, along with two former UND OT students,

who have experience working in Ghana through other service projects. The students also provided these authors with information from a needs assessment they conducted with contacts from Ghana, providing a personal perspective of the needs of Ghanaian caregivers.

Though a strong product, roadblocks to implementation of the manual do exist. The caregiver manual was created with the intention to be used as part of a new service learning project for UND students. Preparation for the fieldwork portion of the learning will be provided through a six-week online course. Both the instructor of the course and the students must know the content of the manual as well as how it is meant to be used in order to effectively present the information to the caregivers in Ghana. Because a majority of the information presented includes hands-on techniques, the authors of this scholarly project would recommend face to face class time be incorporated into the online course to give students the opportunity to learn and practice the handling and positioning techniques included in the manual. Details regarding the coursework and fieldwork of the service learning project are not finalized at this time, and it is possible that the fieldwork may be postponed or even cancelled. In this case, it would be recommended that the manual be adapted to be used by another school or organization working in Ghana.

Another limitation related to use of the manual is that because it is new educational material that has not been piloted, its effectiveness is not yet known. In order to further improve the product prior to use, it is suggested that the manual be shown to a sample of individuals from the general population and/or contacts in Ghana to get feedback on the content and format of the manual. In this way, the authors could make

changes or additions to the manual prior to its use by students in the service learning

project. By staying in contact with the authors of the manual, additional changes could

be made as the manual is actually put into use. Overall, it must be understood by

students and caregivers that the manual is to be used as a guide, not a protocol for

treatment.

Several steps need to be taken in order to measure the usefulness and

effectiveness of the educational manual when put into use. First, feedback can be gained

from students who take the course and participate in the service learning fieldwork on the

usefulness of the manual as a teaching tool. Students can also observe caregivers using

the manual and their ability to use the techniques presented during the fieldwork

experience. Valuable feedback can also be gained from caregivers at the time of

implementation of the manual, both about the manual and the way information is

presented by the students. Finally, follow-up measures can be used to learn if caregivers

in Ghana continue to use the manual and/or have passed on the information to other

caregivers. Other follow-up measures may investigate any changes in occupational

participation of individuals with CP and quality of life of both individuals with CP and

their caregivers. Follow-up contact with caregivers would also allow the authors to find

out about any new needs or concerns that have arisen since the manual was introduced.

As more information is gathered through feedback from caregivers and students

on the effectiveness and usefulness of the manual, improvements can be made in order to

better meet the needs of those individuals using the manual. This may include changing

the way existing information is presented or adding new information. Possible additions

may include sections addressing topics such as behavioral modification, sensory and

cognitive impairments associated with CP, and education regarding specific age ranges such as infancy or adolescence. By making these additions, the manual would be more encompassing, addressing more than only the physical aspects of caring for an individual with CP.

Many opportunities for further scholarly work and collaboration exist in relation to this scholarly project. As mentioned above, the manual could certainly be expanded to address other client factors, including behavioral, cognitive, and sensory impairments related to the CP diagnosis. This presents an opportunity for further collaboration with professionals who have experience in this area. Research can be done with the existing manual, testing its effectiveness and usefulness with the current population. As data is collected and improvements made to the product, the manual may potentially be used as a model for similar target areas or populations. For example, the manual may provide a model for other occupational therapy programs completing similar service learning projects. Lastly, the manual could be published as an educational material to be distributed either in Ghana or other areas where a need is present.

APPENDIX

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