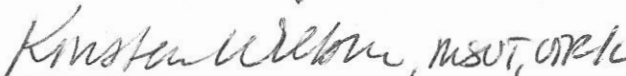


Running head: CREATING A DVD AND RESOURCE KIT

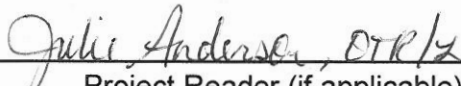
Creating a DVD and Resource Kit: Effective ADL Techniques for Children with Cerebral Palsy
and Their Caregivers for a Clinic in Morocco, Africa

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This project, submitted by Blair Burmark and Carly Valentine, has been approved and accepted
in partial fulfillment of the requirements for the degree of
Master of Occupational Therapy from the University of Puget Sound.



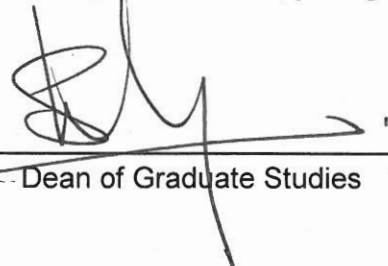
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Abstract

Cerebral Palsy (CP) is a common neurological disorder caused by injury during brain development. The impairments commonly associated with CP include motor and sensory deficits that can significantly impact all areas of occupation, especially activities of daily living (ADL). In countries such as Morocco where the number of healthcare facilities is limited and languages vary, the burden on families to access appropriate care and education can be challenging. Center Asays in Morocco serves children with CP and requested a non-language based DVD for caregivers to provide education on proper positioning for both the child and caregiver during ADL. This project created a DVD that includes instruction for lifting and carrying, range of motion, grooming, sleeping, feeding, and dressing. The DVD is available for the caregivers to watch in the waiting room during therapy sessions and corresponding handouts are provided to increase retention of the information. Through communication with the clinic director, it appears this resource has met needs of the clinic and families.

Key Words: Cerebral Palsy, Morocco, Center Asays, Non-language Based, DVD, Video Modeling, Body Mechanics, Activities of Daily Living, Caregiver

Introduction

The Center Asays is a therapy clinic in Inezgane, Morocco that provides services to children with cerebral palsy ages 6 months to 13 years (Center Asays, 2012). The Center Asays has a need for occupational therapy services for educating parents of children with cerebral palsy [CP] on best practices for handling techniques during ADL and play activities (Boswell, personal communication, February 19, 2012). In order to fill this need, we created videos for parents to watch while at the center with informational handouts for them to take home that provide direction in the areas of occupational need.

Engagement in everyday activities and learning how to perform tasks independently can influence emotional and social health for all children, including those with cerebral palsy. According to the My Child (2014), a CP foundation, occupational therapy benefits children as well as their parents and/or caregivers at any time after a diagnosis. Based on a pilot study published in the American Journal for Occupational Therapy, tentative results suggested that implementing therapy techniques at home may result in better long-term outcomes with children with cerebral palsy (Novak, Cusick, & Lowe, 2007). Occupational therapy can assist children with disabilities to better complete daily occupations (My Child, 2014). The benefits gained from occupational therapy for children with cerebral palsy and their parents align with the values of the American Occupational Therapy Association [AOTA] (2014) Occupational Therapy Practice Framework, which emphasize the importance of engagement and fulfillment in activities of daily living.

After communicating with Ruth Boswell, a physical therapist at the Center Asays, we found that there was a need for non-language based resources for the families at Center Asays to learn how to best help their child perform daily tasks. The families in the area of Inezgane,

Morocco speak a spectrum of languages including French, Moroccan Arabic, Hassaniyya Arabic, Judeo-Moroccan Arabic, Standard Arabic, Moroccan Sign Language, Spanish, Tachelhit, Central Atlas Tamazight, and Tarfit (NewMedia Holdings, Inc., 2015) Since there are so many languages spoken in the area, non-language based videos are necessary to supplement the lack of occupational therapy at the Center Asays and enhance communication with the parents, but also have the potential to assist in the fuller engagement in daily living of the child. Without this resource, families may continue to experience barriers to following healthcare providers' instructions for the home environment.

Background

Morocco

Morocco, located in North Africa, is considered to be a part of the Eastern Mediterranean Region (World Health Organization [WHO] 2014) and is a country rich in culture and history. The population in Morocco is 32,987,206 (Central Intelligence Agency [CIA], 2014), mainly made up of the Arab-Berber ethnic group with 99% of the population identifying as Muslim. Furthermore, the general makeup of Morocco is considered lower middle income, with 8.9% at or below the national poverty line (The World Bank Group, 2015).

Disability in Morocco. According to Hasnain, Shaikh and Shanawani (2008) the lack of access to statistics on disability in Morocco is largely due to the lack of inclusion of people with disabilities in Muslim-based countries; therefore causing a high rate of isolation for and misunderstanding about people with disabilities. The lack of understanding and common misconceptions among the Muslim community may reflect the limited distribution of collected data from the government regarding disabilities in Morocco (Hasnain et. al, 2008). Reduced knowledge and understanding of disability quickly creates a culture for a separated or detached

population. Even though disability among the Muslim community can be misunderstood, the support for family members with disabilities in the Muslim religion is extremely high, especially in reference to the mothers and their children (Daneshpour, 1998).

Healthcare in Morocco. According to a report by the World Health Organization [WTO] (2013) citizens in Morocco have access to between 10.1 and 23.0 healthcare personnel per 10,000 citizens. Due to the inaccessibility of primary health care, resources for prenatal and antenatal care for mothers in Morocco is also limited. Between 2008 and 2012 the proportion of babies with low birth weight was at 15% (United Nations International Children's Emergency Fund [UNICEF], 2013). Morocco has many rural settings and the access to medical services is limited in some areas. The percentage of skilled attendants at birth from 2008-2012 in rural settings was only 55%, compared to 92.1% in urban areas (UNICEF, 2013). In the poorest 20% of the country, the rate of skilled attendants at birth was only 29.5% as opposed to 95.4% among the richest 20% (UNICEF, 2013). According to the World Health Organization (2013), the percentage of women seeking antenatal care (4+ visits) is only 64% in the country and 44% for the region. Unfortunately, the inaccessibility of health care in Morocco coupled by a widespread misunderstanding of disability among the Muslim community has had a large effect on health of children after birth.

Cerebral Palsy

Risk factors. The low rate of antenatal care, lack of skilled attendants at birth, low birth weight, and inaccessibility to medical services for women and children are all risk factors and contributors to the neurological disorder cerebral palsy (CP). The two methods that are used when classifying the reason leading to a cerebral palsy diagnosis include congenital and acquired (Centers for Disease Control [CDC], 2014). Congenital, accounting for 85-90 percent of cases

of CP, refers to the damage to the brain occurring before and during birth (CDC, 2014). There are numerous risk factors for congenital cerebral palsy and include low birth weight, premature birth, multiple births at once, assisted reproductive technology, jaundice or kernicterus in the newborn, various medical conditions of the mother such as thyroid problems or seizures, birth complications, and infections during pregnancy (CDC, 2014). Acquired cerebral palsy occurs in a very small percentage of children diagnosed with CP and appears in the month following birth (CDC, 2014). Causes for acquired cerebral palsy can include infection, injury and complications regarding blood flow (CDC, 2014).

General CP information. If a child experiences infection, trauma or strain in the brain before, during or after birth, a diagnosis of CP is possible. Cerebral Palsy, the most common childhood motor disability (Pakula, Van Naarden Braun & Yeargin-Allsopp 2009) is a chronic condition affecting children and adults throughout the world. Cerebral Palsy is explained by O'Shea (2008) and Pakula et. al (2009) as having an impact on development including motor skills, cognition, communication, sensation, and behavior. According to an article written by O'Shea (2008) regarding CP treatment and prevention, to receive a clinical diagnosis of CP, unmet developmental milestones such as rolling, pulling to stand or walking must be observed. Cerebral Palsy is usually clinically and scientifically classified regarding the main type of movement disorder involved (CDC, 2014). However, there are various types of classification systems used throughout the world, and it usually depends on the institution or reason for classification. According to the Cerebral Palsy Organization (2014), the type of CP can be diagnosed based on severity level, topographical distribution, motor function and the official gross motor function classification system. The physical characteristics include spasticity, uncontrollable movements (dyskinesia) and poor balance and coordination (CDC, 2014).

Symptoms. Spastic cerebral palsy, affecting about 80% of people with the CP diagnosis, is characterized by spasticity (increased muscle tone) and is described by the topographical distribution, meaning the specific body parts involved (CDC, 2014). There are three forms of spastic CP including diplegia or diparesis, hemiplegia or hemiparesis and tetraplegia or tetraparesis. Diplegia or Diparesis affects both lower extremities of the child/adult. Hemiplegia or hemiparesis affects only one side of the body, with the non-affected side developing in a typical pattern relative to age.

Tetraplegia. The most severe form of spastic CP is classified as spastic tetraplegia/tetraparesis, also known as quadraparesis, and is the most frequently treated form of CP in Morocco. Spastic tetraplegia affects all four limbs and potentially affects the trunk and the face. Frequently the child cannot walk and may present with additional developmental disabilities such as intellectual disability, seizures, vision problems and hearing and speech problems (O'Shea, 2008). When describing the impact of CP, the Cerebral Palsy Organization (2014) explains that severe forms of CP usually correlate with significant challenges in accomplishing daily activities.

Treatment. Cerebral palsy is a static disorder at the time of diagnosis, meaning the diagnosis is not progressive, but the symptoms persist throughout the lifespan, however treatment will improve the capabilities of children and their families (Pakula et. al, 2009). The brain has the highest capability for neuroplasticity at early ages so it is very important to treat children with CP to preserve and create new connections within the brain that will support their functionality throughout their lives (Wittenburg, 2009). As a result, diagnosing cerebral palsy early is extremely important. Treatment can include physical therapy, speech therapy, occupational therapy, surgery, orthoses, and medications (CDC, 2014). Through therapy,

children can improve and learn to work around common dysfunction to be more independent in self-care skills. Increased independence in this area decreases the burden on caregivers and results in improved self-efficacy (Shepard, 2012).

Activities of Daily Living

ADL consist of activities that people engage in to perform their personal care needs such as bathing, grooming, and dressing (American Occupational Therapy Association [AOTA], 2014). ADL are “fundamental to living in a social world; they enable basic survival and well-being” (Christiansen & Baum, 1997, p. 156). Children with CP encounter more difficulty than typically developing children with activities of daily living (ADL) (Summers, Larkin & Dewey, 2008). For children with CP, completing different ADL tasks independently are among their top ten preferred goals in therapy across ages, although different ADL were more important to the children at different ages (Lemmens, Janssen-Potten, Timmermans, Defesche, Smeets, & Seelen, 2014). When comparing the priorities of children with CP and their parents, one study found that both rated “adult tasks,” which include ADL, in the top two priorities (Maggs, Palisano, Chiarello, Orlin, Chang, & Polansky, 2011). Because ADL are highly important to children with CP and their caregivers, it would be beneficial to be the main focus of therapy in order to improve quality of life and well-being of both the children and their caregiver.

One element that is a common area of difficulty in all ADL for children with CP is maintaining proper positioning to perform each task. Children with CP tend to have patterns of movement that are different than typically developing children and can increase the likelihood of contractures and deformities as well as prevent normal physical development (Finnie, 1974). One of the key symptoms that affects children with CP is abnormality in the head, neck, and spine muscles, which directs and initiates during many functional movements and ADL (Bobath,

1967). In addition to positioning, being able to actively direct movement is essential for play, feeding, grooming, dressing, and many other ADL. One study that followed a group of children who were introduced to a functional sitting position found that after five years, the children who used therapeutic positioning had improved slightly while the children who had not deteriorated in function (Myhr, Wendt, Norrlin, & Radell, 1995, p.587). By using key strategies in everyday movement of the child, both the child and the parent can avoid reinforcing contraindicative movements and increase independence of the child in ADL.

Effects of CP on the Caregiver

In addition to motor and cognitive deficits, psychological and economical strain on both the patient and the family is a common result of a CP diagnosis. One study that looked at a group of caregivers for children with CP found that caregiver demands, such as the level of the child's diagnosis or behavioral patterns, are a strong predictor of the physical and psychological well-being of the caregiver (Raina et al., 2005). Another study conducted in Malaysia also reported that stress levels of both the children with CP and their mothers was significantly higher than that of a control group that consisted of mothers and their children without disability that attended the pediatric clinic (Ong, Afifah, Sofiah, & Lye, 1998). An article published in the CDC Monthly and Mortality Weekly described the average lifetime costs, recognizing the costs will vary with severity of diagnosis, for a person with CP is \$921,000 (Bhasin, Brocksen, Avchen & Van Naarden Braum, 2006). Therefore, it can be inferred that if caregivers are given support and low cost strategies to work with their child, the well-being of both the child and their caregiver can be improved.

Effectiveness of Video Modeling

Parents in Morocco could benefit from learning skills and strategies to help their children with CP complete their ADL more efficiently. Without a trained occupational therapist, alternatives are needed and, a low cost, non language-based, and effective medium is necessary to teach techniques to the parents. Video modeling is a strategy used by many therapists to teach skills by demonstration to patients or their caregivers (Burdick and Biele, 2014). Video modeling is low cost and has been proven to be effective in teaching therapy techniques (Gagliano, 1988). Video modeling has not only been shown to increase knowledge, but also to decrease anxiety (Gatchel, 1986), improve emotional response, and potentiate learning (Uzark, Rosenthal, Behrendt, & Becket, 1985). In a study by Nay (1975), it was found that parents who received information about parenting skills using video modeling did significantly better than those who received the information in other forms in a laboratory test. Videos lessen the need for a therapist to be present and therefore decreases the cost for the patient and the treatment time required by the practitioner (Gagliano, 1988). One area that was found to not be as effective in video modeling is long term retention (Gagliano, 1988), so having a picture-based reminder of information in a paper form could give recipients a visual reminder of information in a video after the fact and help with recall. Video modeling is an ideal medium to teach parents of children with CP, especially in a situation where it is not possible to use language to convey the information.

Center Asays

The Center Asays is a clinic located in Inezgane, Morocco near the west coast of the country (Center Asays, 2012). The vast majority of the center's clients are children between the ages of 6 months to 13 years with cerebral palsy, the majority of whom have spastic tetraplegia. Some clients travel as long as an hour and a half in buses or taxis to get the services provided at

the center (R. Boswell, personal communication, April 10, 2014). The center no longer has an occupational therapist on staff and other staff have expressed a need to educate parents on a variety of strategies normally taught by the occupational therapist in the areas of mobility, handling, and ADL (R. Boswell, personal communication, February 26, 2014). By creating a DVD with strategies for these areas of need, we have enabled parents to watch and learn while their child is in therapy. In order to accommodate the plethora of languages and cultures in Morocco, including Moroccan Arabic, Classic Arabic, French, and Berber (Hachimi, 2012), we created a non-language based DVD. A resource manual containing picture-based handouts outlining the strategies taught in the video for parents reinforces the information in the videos and allow parents to take home a physical reminder of the content they learned in the videos. The therapists are also able to tailor the home exercises and strategies that they chose to give families so that it fits their needs and can serve them best. By illustrating and demonstrating information about ADL for children with cerebral palsy and handling techniques for their parents, we have filled a need in this busy clinic. In addition to filling the need for occupational therapy instruction, we have also strived to decrease the prevalence of bad habits in the families of children with cerebral palsy, which ultimately gives the child the opportunity to be more comfortable and functional in their daily life.

Purpose Statement

The purpose of this project was to create a non-language based video and resource kit to educate parents of children with cerebral palsy (CP) attending therapy sessions at the Center Asays on proper handling and positioning techniques for performing activities of daily living (ADL) in order to enhance independence and safety and reduce caregiver burden.

Overview of the Project

Center Asays provides therapy services to children between the ages of 6 months to 13 years with the diagnosis of cerebral palsy. Families sometimes travel up to one and a half hours to attend the clinic and to receive services. As of May 2015, the clinic no longer provides occupational therapy services. Therefore, to provide parents with adequate therapy recommendations during their visit as well as information to take home, we have created a non-language based video and supplemental handouts. Within the DVD, there are six distinct chapters the parents are able to navigate through. The chapters include feeding, dressing, sleeping, teeth brushing, range of motion and carrying the child. Within each chapter, there is a series of videos demonstrating proper methods to perform each type of activity. The DVD incorporates specific drawings from the handouts throughout each chapter to emphasize certain techniques and positions of the child and caregiver. In addition to a DVD, there is a resource kit with supplemental handouts corresponding to the videos. The resource kit has the same chapters as the DVD, using drawings to display the proper handling and positioning methods. Behind each chapter tab, there is a collection of handouts to give to the families to take home.

Center Asays “exists to improve the lives of children with cerebral palsy... [and] strive[s] to give hope to these families through therapy, education, encouragement, kindness and love” (Center Asays, 2012). With a resource kit and DVD emphasizing the importance of certain handling and positioning techniques, the Center is able to fulfill their mission statement by educating and encouraging the families of the children. By educating the caregivers and families with the videos and take-home resources, the children may then directly benefit from the education of therapy techniques by implementing the techniques at home, increasing the

potential for growth and improvement. Ruth Boswell, a physical therapist at Center Asays, was integral in formulating the idea of the videos and resource kits for the families. Ms. Boswell knows her clients extremely well and was able to understand the needs of the parents as well as children. The children come to the Center for physical therapy twice a week and speech therapy for a half hour each week. Due to the limited time with the children and families, it can be difficult for the therapists to allot time out of their session to talk to the family about occupational therapy activities. The therapist can now use his or her professional knowledge to utilize the resource kit and ensure parents are receiving education on additional techniques.

Project Goals and Objectives

GOAL 1: Parents will have increased knowledge regarding safe implementation of occupations with their children after watching the DVD and receiving handouts.

OBJECTIVE 1: After watching the DVD and receiving handouts, parents will be able to indicate one technique to use with occupations addressed in the video and shown in the handout that are specific to their child's needs to a healthcare staff at the Center Asays.

OBJECTIVE 2: After watching the video and receiving handouts, parents will be able to identify one general contraindicated technique that is applicable to their child's ADL.

GOAL 2: Healthcare staff at the center will report that they consider the materials beneficial to families that attend the clinic.

OBJECTIVE 1: After watching the video and receiving handouts, healthcare staff at the center will complete a post-implementation survey and report a cumulative score of 25 out of a possible 35 points indicating general satisfaction with the materials.

OBJECTIVE 2: After watching the video and receiving handouts, healthcare staff at the center will complete a post-implementation survey and report two or fewer concerns regarding the materials.

Procedure

This project began by compiling a list of main points in positioning and handling for each ADL section that was to be included in the video. In order to find this information we researched practical techniques in performing ADL with children with cerebral palsy (CP) and continued speaking with experts in the area including Lucretia Berg, OTR/L. After creating the content for the video, we found a family with a child with CP who was willing to be featured in our video and set a day and time to complete the filming. We also created storyboards depicting the anticipated content of the video in order to make the day of filming go as smoothly as possible. We had an expert occupational therapist, Lucretia Berg, OTR/L, at the filming to provide quality control and make sure that the techniques shown in the video were correct and useful to the potential viewers.

After the filming of the video was completed, we completed the video editing using iMovie. Upon completion of film editing, we created the resource manual using the information that we compiled for the video regarding the proper techniques and particularly the “do’s and don’t’s” of each ADL for children with CP. We are creating line drawings depicting the scenes

from the video. The line drawings are also included in each chapter of the DVD to create a uniform presentation between the DVD and resource kit.

We completed the video editing and sent a sample chapter to Center Asays along with a survey via Dropbox. Once we received the survey back, we edited all necessary changes and sent the final product back to Center Asays. They can now use specific sections with clients that it is most appropriate for. We also provided the post-use questionnaire for parents/caregivers, and a critique questionnaire for therapists at the center to assess whether the video is a useful and effective tool. The questionnaires were written in English, handed out and translated by Ms. Boswell, and touched on areas such as ease of use, clarity of information, level of applicability to the clinic and clients, and likelihood of future use.

The following are skills and knowledge that we used and developed during the project creation process: skilled observation, professional communication skills, professional writing skills, collaboration skills, problem-solving skills, time management skills, creativity, therapeutic use of self, listening skills, video creation skills, understanding of principles of professional video standards, knowledge of proper ADL techniques in children with CP, knowledge of the needs of families and therapists at the Center Asays, knowledge of the unique culture of the region and center, knowledge of non-language based techniques, ability to convey techniques in video format effectively.

Implications for Occupational Therapy

The Person-Environment-Occupation Model (PEO) (Law, et al.,1996) was created by occupational therapists to describe the complex and ever changing relationship between the person, the environment that they exist in, and the occupation that they are participating in (Brown, 2014). When the three factors have a “goodness of fit,” and overlap in a productive way

it results in occupational performance (Brown, 2014). Occupational therapists use the PEO model to frame their practice and address all areas of the person's life that are affecting their occupational performance in a dynamic way.

For our project, we used the PEO model to increase occupational performance of children with cerebral palsy (CP) and their caregivers at a clinic in Morocco, Africa. The video that we created trained parents on effective strategies for performing activities of daily living (ADL), particularly teeth brushing, sleeping, dressing, carrying, and range of motion with their children. In the absence of a licensed occupational therapist at the clinic, our video acted as a supplemental resource to current therapy. Educating the parents changed the children's social environment by providing them with the knowledge and skills needed for the implementation of effective ADL strategies. It also changed the way that the families perform the ADL in the video, thereby changing the occupation. Improving the environment and occupation created a better fit between environment, occupation, and the children with CP and therefore facilitated increased occupational performance in the ADL that we addressed.

Occupations, as defined by the American Occupational Therapy Association (AOTA, 2014) in the OT Practice Framework, include ADL, instrumental activities of daily living (IADL), rest and sleep, education, work, play, leisure, and social participation. The symptoms and impairments, referred to by AOTA (2014) as client factors, associated with CP such as high and low tone, decreased sensation and decreased trunk control can significantly impact all the areas of occupation, especially ADL. At Center Asays in Morocco, high tone is an impairment seen by most of the families attending the clinic. High tone can inhibit performance and independence in tasks such as grooming, dressing, sleeping, and play if it is not appropriately addressed. By creating a DVD for parents of children with cerebral palsy in Morocco to watch

while their children are receiving other therapy services, we increased awareness of therapeutic techniques to use when their children are performing ADL. The parents gain knowledge regarding the facilitation of ADL with a child with high tone, limited trunk control, and impaired motor control. As a result, the family may potentially be able to incorporate the techniques on a daily basis. Integrating various therapeutic techniques during ADL with their children could lead to increased independence, increased performance skills (AOTA, 2014) and improved safety with the parent's own body mechanics. The ultimate goal of occupational therapy is participation and engagement in everyday activities, and by increasing performance skills; the children will be able to develop and engage in performance patterns such as roles, habits and routines, as well as other occupations such as social participation and play (AOTA, 2014).

Limitations

Special considerations for this project include the cultural influences in Morocco, language barrier, resources needed for duplication, and caution against using the videos in place of available therapy. The video and resources for the Center Asays in Morocco were created with the cultural and environmental traditions of Morocco in mind, however we have not travelled to Morocco or seen the clinic first hand. We were restricted to attaining knowledge of the culture by doing research and speaking to therapists in the region. Many of the resources and access for families in Morocco may be different than other countries around the world. Positioning and handling techniques are tailored to the families and caregivers living in Morocco. We were also limited in our ability to convey complex information by creating the video and resource kit without using language. If the audience that we are creating the project for spoke English we may have been able to include more information and give more clear instructions. In addition, if the video and/or resource manual is to be duplicated and used, the

need for a computer, printer and television with DVD player are necessary to implement the project in another clinic and/or therapy center. Finally, the DVD is not meant to replace an occupational therapist and should act as a supplement to other therapy. The DVD and resource manual are to be used when the access to an occupational therapist is not possible.

Sustainability

In order to ensure sustainability for the project within Center Asays, we have taken steps to allow this project to be accessed electronically as well as physically. The project video and supplemental handouts are not only being delivered in printed form through mail, they are being delivered through Dropbox on the internet. Ms. Boswell, from Center Asays, has confirmed the clinic has access to the Internet and a computer. By delivering the project materials online, Ms. Boswell will always have access to the materials even if the physical materials are lost or damaged. This method of delivery will ensure sustainability over a long period of time and reduce the amount of maintenance Ms. Boswell or the center will need to do to keep the project in working condition. This will also allow the clinic to move the content of the video to different types of physical disks or newer technology as it is created so that it can be viewed for many years to come.

Outcomes

We sent the DVD and resource kit to Center Asays in Morocco via mail and Internet. Ms. Boswell reviewed the content of the DVD and sample resource handouts and gave positive feedback through an email. Ruth stated, "As others have looked at this video clip and the handouts, they are able to understand and show how to follow through with something like this

at home”. We sent a post-use survey to be filled out by therapists and parents, and have not received a response as of the conclusion of our academic year.

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