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Addressing Self-Care at Home: A Family-Centered Program for a Pediatric Client with a

Complex Medical History

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Note: This document describes a capstone dissemination project reflecting an individually planned experience conducted under faculty and site mentorship. The goal of the capstone experience is to provide the occupational therapy doctoral student with a unique experience whereby he/she can demonstrate leadership and autonomous decision-making in preparation for enhanced future practice as an occupational therapist.

Abstract

Children who are born with a congenital diaphragmatic hernia (CDH) often must deal not only with the condition itself, but with other debilitating health conditions as well. The client around whom this case study is centered is no exception, and he struggles with completing self-care tasks independently. While caregivers often have the best interest in mind for their children, they may not have the time or energy to implement therapeutic recommendations at home. This case study implemented a home program to address the self-care concerns of an 8 year-old boy and his family. Acquisitional and family-centered care techniques were utilized. The Canadian Occupational Performance Measure (COPM, Law et al., 2005) and the Pediatric Evaluation of Disability Inventory (PEDI, Haley et al., 1992) were used to measure the client's progress over the course of 10 weeks. The Bruininks-Oseretsky (BOT-2, Bruininks & Bruininks, 2005) was also administered to gain baseline information regarding the client's motor functioning. Intervention techniques focused upon opportunities to practice self-care occupations, positive reinforcement, implementation of visual schedules and compensatory strategies, and improved communication between family members. The results of the case study were improvement of independence with self-care tasks, improved communication between family members, and decreased stress of family caregivers.

Introduction

The purpose of this case study was to implement a family-centered, self-care home program for a pediatric client with a complex medical history. The client served is an eight year-old male whose name is Alex. Alex lives with his natural parents and two younger siblings, a sister and a brother. Alex is in X grade in a public elementary school and is well-liked by his classmates and teachers. Underlying his quite “normal” appearance, however, are many functional barriers which make participation in everyday school and self-care occupations quite challenging.

Alex was born full-term with a congenital diaphragmatic hernia (CDH). A congenital diaphragmatic hernia (CDH) occurs when the diaphragm in the chest wall does not fully develop in utero. The result of this lack of development is a hole between the chest and the abdomen. The presence of this hole allows the organs in the abdomen to travel upwards into the fetal chest space. The presence of organs (such as the stomach, intestine, liver, spleen, and kidneys) in the fetal chest space means that the lungs do not have the room they need in order to grow to a full, normal size (University of California, San Francisco: The Fetal Treatment Center, 2009). A CDH is primarily characterized by a variable level of pulmonary hypoplasia (e.g., underdeveloped lungs), a decrease in pulmonary vasculature and a dysfunction of the surfactant system of the lungs (e.g., a lipoprotein complex that helps to reduce surface tension in the lungs). CDH occurs in 1 of every two to three-thousand live births (Steinhorn, 2009).

As a result of his condition, Alex was born with only one lung. While in the NICU at Cincinnati Children’s Hospital following his birth, Alex was placed on a heart-lung machine as an attempt to improve his compromised breathing. As a consequence of being on this machine, a blood clot formed that resulted in the right, internal carotid artery becoming blocked. Because of

this blocked artery, Alex suffered a stroke when he was 8 days old. The stroke occurred in the right side of his brain; thus, the left side of Alex's body has been affected such that movements occurring here are slow and somewhat uncoordinated.

Following Alex's initial 90 day stay in the NICU of Cincinnati Children's Hospital, he underwent 5 surgeries to correct the hernia of his diaphragm. He was fed by a gastrointestinal tube (G-tube) for the first 5 years of his life and received early intervention services prior to preschool. Early intervention included services provided by occupational, physical, and speech therapists. Alex received feeding therapy at the Toledo Hospital prior to the removal of his G-tube and attended the Toledo Hearing and Speech Center for occupational therapy services prior to receiving occupational therapy at school. Additionally, Alex received vision therapy services in early 2009.

Considering the wide range of services that Alex has received throughout the course of his young life, one might rightly assume that he has more underlying issues besides that of his pulmonary condition. Indeed, Alex has other co-existing conditions alongside of his CDH such as gastro-intestinal reflux, migraines, auditory processing dysfunction, asomatognosia, scoliosis, and epilepsy. Additionally, Alex has difficulty putting on weight, and may therefore soon be placed on a growth hormone.

Alex is not the only survivor of CDH to suffer health problems beyond the initial pulmonary concerns present at birth. Lund et al. (2004) reported the results of study demonstrating that there is a broad range of extrapulmonary problems that can exist amongst high-risk patients with CDH who survive. The researchers began a multi-disciplinary follow-up clinic in 1990 for patients with CDH. Since the beginning of the program, the authors collected follow-up data on 33 individuals who survived high-risk CDH at birth. Results showed a broad

range of difficulties extending beyond pulmonary concerns. Examples of deficits that were found among survivors include hearing loss, seizure activity, developmental delays, vision problems, growth and nutrition problems, scoliosis, pectus excavatum (e.g., a sunken-in chest), and vesicoureteral reflux (e.g., urine flowing backwards into the ureters).

Considering all of the extrapulmonary problems that Alex has experienced and been treated for, it is not surprising that that he would struggle to functionally complete many occupations of daily living (ODL's) when compared to their same-age peers. It is important for children to be able to complete ODL's (or self-care occupations) independently as "independent engagement in self-care occupations can foster self-reliance; self-esteem; and, for socially oriented occupations such as mealtimes, a sense of continuity and belonging," (Frank, 1994, as cited in Kellegrew, 1998, p. 457). Additional benefits to a child's participation in his or her own self-care include "maintaining and improving body functions (e.g., strength, endurance, range of motion [ROM], coordination, memory, sequencing, concept formation, and body image)," meeting role expectations required in a community, and allowing the caregiver(s) to have more time and energy for other occupations (Shepherd, 2005, p. 522).

Occupational therapy interventions can be useful in improving performance of self care occupations. Kellegrew (1998) completed a study in which 3 caregivers were told to monitor the frequency at which they presented opportunities to the children in their care to complete various self-care tasks. This method was utilized as Kellegrew (1998) believes that "participation in self-care activities or occupations depends on two primary components: ability and opportunity," (p. 457). Results of the study showed that all three of the children "showed a marked increase in their independent engagement in the self-care occupation," (p. 461).

The results of Kellegrew's study are consistent with the approach to therapy established by the Acquisition Frame of Reference (AFR, Royeen & Duncan, 1999), a frame of reference that is highly applicable for use with implementing a self-care home program for Alex. Royeen and Duncan (1999) assert that the AFR "focuses on the acquisition, or learning, of specific skills required for the optimal performance within the environment," (p. 377). The acquisition of skills is effected by the interaction between the environment that the child is in and the child's behavior. Similar to Kellegrew's (1998) beliefs regarding the pre-requisites to participation in self-care actually occurring, the AFR asserts that "if the environmental content does not afford or elicit certain behaviors, they will not emerge," (p. 380). Essentially, the opportunity for the child to participate in the self-care occupation must be present.

Other components of the AFR include providing positive reinforcement to elicit the desired behavior(s), as "skill development...is dependent upon positive (rewards)," (p. 382). Negative reinforcement is also commonly used within the AFR, as this is a method of not acknowledging and thus not reinforcing an undesirable behavior. Schedules of reinforcement are commonly used within the AFR, and are used as a way to organize the reinforcement that is occurring.

Other components of the AFR include shaping and generalization. Shaping refers to "rewarding a close approximation to a desired skill," (p. 384), while generalization refers to the process whereby a learning behavior or skill becomes more automatic and the performance of the behavior itself proves to be rewarding to the child. The three major theoretical postulates of the AFR are that skills are acquired as a result of reinforcement, function is not dependent on the particular developmental stage that the child is in, and behaviors result from interaction with the environment that the child is in.

Consideration of the AFR and Kellegrew's (1998) findings suggest that increased opportunities to practice occupations plus family involvement are key in the acquisition of skills. Therefore, it seems only natural to ask caregivers to incorporate more "practice time" in a child's schedule to acquire certain skills. However, implementing suggestions made by a therapist can be extremely challenging and overwhelming. For example, Humphry and Case-Smith (2005) state that "service providers can be a source of threat to the family's time and emotional resources," (p. 129). Humphry and Case-Smith offer the perception of a mother who had a child with a disability and a typically developing child as well. This mother stated that her family "experienced the burden of home programming," as physical, occupational, and speech therapists all made "separate recommendations," that required an hour and a half each day (Greene, 1999, as cited in Humphry and Case-Smith, 2005). Additionally, therapists often make recommendations surrounding the needs of the child entirely while forgetting to inquire about the needs of the child's caregivers as well.

In an attempt to appropriately deal with these limitations, therapists can implement the Family Centered Care Approach (FCCA) (Rosenbaum et al., 1998). Ideas surrounding this approach originated from Carl Rodger's work with families who had difficult children. Many authors and organizations since have discussed and presented principles that follow a family-centered model. For example, there is now a much greater focus on partnership and collaboration between health care professionals and families rather than an authoritative type approach. The FCCA has three basic tenants. The first is that parents are the most knowledgeable people concerning their children, and parents generally want the best for their children. The second tenant is that families are each unique and different. The third tenant is that the child is optimally functional when within a supportive family and community network. Other important

components of the FCCA include the services being “provided in ways that are flexible and responsive to family needs, concerns, and priorities,” and that services are based upon collaboration with the child’s family rather than just the opinion of the therapist alone (Brown, 2004, p. 349).

Rosenbaum et al. (1998) conducted a review of literature to establish the overall effectiveness of the FCCA. Fourteen articles were analyzed. The authors found “considerable evidence of the effectiveness of a family-centered approach to service,” when elements of the FCCA had been incorporated (Rosenbaum et al, 1998, p. 13). Some positive results of incorporation of the FCCA included increased caregiver satisfaction, decreased stress, increased parental involvement in home treatment programs, and improved psychological well-being of pediatric clients and their families. Based upon previous positive results of use of the FCCA, it was felt that this approach would be very appropriate for use with Alex and his family. This case study implemented the AFR with the FCCA to enhance performance of self-care occupations in a pediatric client with a complex medical history while considering his family simultaneously.

This case study was completed as a part of a Capstone project for a doctorate student (AMW). The doctorate student (AMW) was under the guidance of a pediatric occupational therapist (JRP) as well as a faculty mentor (AEM). The Capstone project began in January of 2010 and commenced in April of 2010. Informed consent was provided by the client’s family. The names have been changed to protect the identity of the client and his family.

The client at present

Alex is currently a healthy and medically stable second grader who enjoys playing soccer and his family’s “Wii” game system. While Alex has some difficulties with the academic content presented to him in school, he has an exceptional work ethic and a very pleasant social

demeanor. Intelligence test results from April of 2009 show that Alex has a full-scale IQ of 78, indicating that he is functioning in the borderline range of cognitive ability. Overall, Alex transitioned well to first grade, with his teacher indicating that he was a pleasure to have in class, and that he is polite and well-liked by his classmates. His teacher indicated some concerns with reading comprehension and sequencing.

At the beginning of the case study, Alex was receiving occupational and speech therapies in school. These therapies were provided by the same agency as the doctorate student was working with to complete her capstone project. Alex's occupational therapy goals were primarily academic in nature, as is required by law for in-school occupational therapy services. Thus, Alex's goals are as follows: (1) during written tasks and with initial reminders, Alex will appropriately align letters (50%) and size letters (80%) to grade level expectation 3/5 trials, (2) during class assignments, Alex will print short answers with 50% accuracy in precise pencil control, 3/5 trials, and (3) with initial reminders to review prewritten sentence, Alex will identify significant errors (those completed with less than 50% accuracy) in alignment, size and form (precise pencil control), 3/5 trials. At the commencement of the self-care home program, Alex was making adequate progress towards these goals.

Even though Alex was making progress towards his occupational therapy goals, these goals were completely academic in nature. Alex's mother was still concerned regarding Alex's lack of independence in his self-care routine at home. Alex greatly struggled with seemingly "simple" self-care occupations such as buttoning a shirt, zipping a jacket, tying his shoes, putting toothpaste on his toothbrush, showering, pouring liquid into a glass, and "buttering" a piece of bread. Alex's increased need for help with these occupations frustrated him, and often led to "meltdowns" at home. Additionally, the assistance that Alex required to complete these

occupations meant that his parents had less time to complete their own occupations. Prior to the case study being initiated, Alex's parents had desired Alex to receive additional therapy services; however, their insurance did not cover such services. Therefore, Alex's parents were very pleased to have the opportunity to participate in the case study to receive more information that might help Alex to function more independently at home.

Assessment

The Self-Care Domain portion of the Pediatric Evaluation of Disability Inventory (PEDI) (Haley et al., 1992) was the first assessment that was completed. This assessment was chosen in order with its compatibility with the Family Centered Care Approach. The PEDI is meant to “sample key functional capabilities and performance in children from the ages of 6 months—7.5 years.” (p. 3). While Alex exceeds the 7.5 year age limit, this assessment was felt to be appropriate due to the delays that he experiences in the area of self-care compared to his same-age peers.

Parts I and II of the Self-Care Domain of the PEDI were administered via an interview with Alex's mother Natalie. On Part I of the self-care portion of the PEDI, the parent checks one of two boxes: that his or her child is either “unable,” or “capable,” of completing a certain self-care task. If the child is unable to complete a certain task, he or she scores a 0 for that particular item. If the child is able to complete the task, he or she receives a score of 1. All items are tallied for the Self-Care Domain Sum. Part II of the Self-Care Domain portion is meant to measure the amount of caregiver assistance and modification that the child requires in order to complete particular self-care occupations. A parent completing this portion scores his or her child on a scale of 0—5, with a score of 0 meaning that the child needs total assistance to complete a task and a score of 5 indicating that the child is independent with the task.

The results of the PEDI as completed by Alex's mother show that Alex has a relative moderate level of ability to complete self-care tasks independently (scoring a 63.9 out of 100, with a standard error of 1.7) (Table 1). Additionally, results showed that Alex requires a moderate level of caregiver assistance when completing self-care tasks (scoring a 71.1 out of 100, with a standard error of 4.1). While the overall interpretation of the PEDI is not poor in and of itself, closer examination of the items that Alex is unable to do independently reveal a greater amount of deficit. For example, Natalie stated that Alex is unable to pour liquid from a carton or pitcher, prepare his toothbrush with toothpaste, wash his entire body thoroughly, button, zip, tie shoelaces, and manage his clothing before and after toileting, among other things. These are skills that would normally be expected of a typically developing 8 year-old child. .

The Canadian Occupational Performance Measure (COPM) (Law et al., 2005) was the second assessment that was completed. This assessment was completed in order to gain a greater understanding of how Alex's mother, Natalie would choose to prioritize areas of intervention for Alex. The COPM fits nicely with the Family Centered Care Approach as it allows the therapist to focus on the specific concerns and satisfaction levels of the client and/or his or her family regarding specific occupations. The COPM contains three overall content areas: self-care, productivity and leisure. Within these three areas, specific occupations are named via interview by the client and/or his or her family member, and then the five most important occupations are rated on a scale of 1—10 in terms of the client's level of performance, the client's/caregiver's satisfaction regarding completion of this occupation, and the level of importance in terms of mastery of the occupation. The self-care portion of the COPM was the only section completed, as it is most applicable with a home self-care program.

Within the area of self-care, Natalie had difficulty prioritizing only five occupations as being more important than others for Alex to work on. However, over the course of the COPM interview, five occupations did emerge as being slightly more important than the others. These five occupations were (1) showering, (2) tying shoes, (3) brushing teeth, (4) buttoning and (5) zipping. Pouring liquids from a container and buttering a piece of bread were also areas of concern, though not rated quite as high. As rated by his mother, Alex's total performance score was 4 out of 10 while his total satisfaction score was 3.2 out of 10 (Table 2). Another important piece of information that was gained from the interview is that Alex greatly struggles with transitions at home, apparent performance anxiety, and perfectionism. For example, Alex might have a meltdown if he is asked to transition from playing a video game to taking a shower, a self-care task that is difficult for him. Additionally, Alex may have a meltdown if he does not perform an occupation well (e.g., shoe-tying) that he was asked to perform by one of his parents.

Finally, the Bruininks-Oseretsky (BOT-2, Bruininks & Bruininks, 2005) was administered in order to gain an understanding of Alex's present level of motor functioning. The BOT-2 was chosen to provide a baseline measure of the underlying motor skills which may need to be addressed. The fine manual control, manual coordination, body coordination, and strength portion of the strength and agility subtests were administered to Alex over the course of 3 sessions divided amongst 3 weeks. Results of the BOT-2 can be additionally viewed in Table 3.

The fine manual control portion of the BOT-2 will be reported with two scores due to Alex being permitted to cut out a circle with his right and left hands; the BOT-2 specifies that the cutting should be completed with the child's dominant hand (Alex's right), however, Alex reported that he consistently cuts with his left and is more comfortable doing so. Thus, both were permitted and will be reported. When cutting out a circle with his right hand (dominant), Alex

received a scaled score of 8 on the fine manual control portion of the test, which shows that he is in the 7th percentile. When cutting out a circle with his left hand (non-dominant), Alex received a scaled score of 10 on the fine manual control portion, showing that he is in the twelfth percentile. Scaled scores “relate one examinee’s performance to the performance of a pertinent reference group,” made up of individuals who are about the same age as the child being tested (Bruininks & Bruininks, 2005, p. 27). The BOT-2 scaled scores have a mean of 15 with a range from 1 to 35. Alex’s age equivalency for this test ranges between 5.4—5.11 years of age with Alex scoring more poorly on the fine motor integration subtest versus the fine motor precision subtest.

Alex received a scaled score of thirty-seven on the manual coordination portion of the test, indicating that he is in the 10th percentile for this category. His age equivalency for this test ranges between 4.10—8.2 with Alex scoring more poorly on the manual dexterity subtest versus the upper-limb coordination sub-test. He received a scaled score of 42 for the body coordination subtest, showing that he is in the twenty-first percentile for this category and has an age equivalency range of 5.6—6.2. Alex scored more poorly on the bilateral coordination subtest rather than the balance subtest. Lastly, Alex received a scaled score of 8 for the strength portion of the strength and agility subtest, indicating an age equivalency of 5.2—5.3 years of age for this subtest.

An important part of the assessment phase included the observation that took place within Alex’s home. This observation was completed in order to have a more complete picture of not only the occupations that Alex typically completes within his home, but also how Alex’s family dynamics and environment effect his performance. The observation took place during the evening in order to observe several of the important self-care occupations that naturally occurred

during this time period. The occupations that were observed during this visit were buttoning, shoe tying, bath time, brushing teeth, and donning pajamas. Several important observations were made during the first home observation.

First, it was noted that Alex quickly became frustrated to the point of a melt-down when he was not able to perform a self-care occupation asked of him by his mother while others were present (e.g., during the time of the observation, Alex was not able to tie his shoe via the one loop method his mother suggested—this caused him to become distressed). Another observation was that Alex seemed confused and overwhelmed by the motor planning required of some occupations, such as the bath. For example, during bath time, Alex required multiple verbal cues from his mother regarding what steps of the bath should come next.

Also, it was noted that Alex preferred and felt more comfortable completing self-care occupations when he was able to stabilize objects against his body or another outside, stabilizing force. For example, Alex draped his washcloth over the edge of the tub in order to squeeze body wash onto it. He also stabilized his toothpaste against the side of his body while squeezing the paste out until he was cued by his mother to hold the toothbrush over the side of the sink. Lastly, it was noted that Alex had a tendency to avoid crossing his body's midline (e.g., washing his left leg and foot with his left hand). Natalie confirmed this observation, offering the additional example of Alex's method of playing air hockey. She noted that Alex often hops from one side of the air hockey table to the other to hit the puck rather than crossing his body's midline to hit it.

Once all of the information from the assessments and informal observation was compiled, goals were written via collaboration with Alex's parents, the student's faculty mentor (AEM) and the student's site mentor (JRP). It was agreed that home therapy would begin and take place over the course of ten sessions. It was understood that these sessions were meant to present

opportunities to and encourage active participation from Alex on the various self-care skills that were such a struggle for him. Alex's mother, Natalie, was open to receiving ideas and feedback throughout the entire home-therapy process. This open line of communication proved to be very beneficial as the home therapy sessions commenced.

In-Home Therapy Goals

Upon the results of the assessments, the following seven self-care goals were set for Alex. These goals were as follows: (1) with use of a visual picture schedule and compensatory bath mitt, Alex will wash and rinse his whole body and hair while standing in the shower, (2) Alex will independently engage and zip zipper on donned coat or jacket 2/3 trials, (3) Alex will align and fully button 90% of given buttons on donned clothing, (4) Alex will independently pour 8 oz. of liquid from a container into a glass while simultaneously stabilizing the glass with his non-pouring hand with no more than 2 spills, 2/3 trials, (5) Alex will independently "butter" a piece of bread while simultaneously stabilizing the bread with no more than 3 mis-marks 2/3 trials, (6) while stabilizing his toothbrush against the counter with his left hand, Alex will place toothpaste on the brush with his right hand with no more than 2 mis-marks 2/3 trials, and (7) with use of compensatory shoe laces, Alex will independently tie his shoes using a double-loop method 3/5 trials.

It was inferred that these goals would have meaning and purpose to Alex and to his family members for several reasons. First, independence in self-care occupations is highly valued in society and specifically by Alex's family. Secondly, Alex's mother, Natalie, admitted that self-care occupations were of concern to her and that she was highly motivated towards increasing Alex's independence in this area. Additionally, increased independence with self-care

tasks would allow Alex to function more competently and comfortably within his various roles, such as that of “student,” “son,” and “sibling.”

Intervention

Beginning March 8, 2010, Alex received ten in-home therapy sessions over the course of six weeks. Each session lasted approximately one hour. The in-home sessions focused on providing opportunities for Alex to practice various self-care skills, implementation of visual schedules and various compensatory strategies, creating opportunities for Alex to effectively communicate his perceived performance to his mother, and rewarding participation in self-care occupations. Additionally, focus was given to occupations that would encourage Alex to incorporate bilateral coordination at his body’s midline and crossing his body’s midline. A full occupational synthesis and re-synthesis was written with additional information concerning inferred meaning and purpose that the client had throughout one particular therapeutic intervention. This synthesis/re-synthesis may be referenced in Appendix A.

Opportunities to Practice Self-Care

Upon talking with Natalie after the initial in-home observation of Alex, Natalie admitted that she and her husband have not always provided Alex with increased opportunities to practice self-care occupations. For example, Natalie stated that since Alex seemed so confused and overwhelmed by the process of taking a shower, Alex’s father, Ron, would simply allow him to take a bath and would then bathe Alex himself. Natalie admitted knowing that Alex is capable of greater performance than he is often allowed. Natalie was encouraged to allow Alex to perform self-care occupations as independently as possible, even if it takes a bit of increased time. An example was given to Natalie: if the family is preparing to leave for an outing, she or Ron should

ask Alex to get his shoes on and tie the laces several minutes before Alex's siblings don their shoes. In this way, Alex will not feel as hurried and will most likely be more successful with the task he is asked to perform.

Implementation of Visual Schedules

Natalie indicated that Alex greatly struggles with the sequencing and motor planning aspects of multi-step self-care occupations. This same observation was made during the initial in-home observation of Alex. For example, it was noted that Alex required an increased amount of verbal prompting to complete all of the steps of washing himself while he was in the bathtub. Natalie offered another example for illustration. Several evenings before in-home therapy began, Natalie asked Alex to go to the bathroom and brush his teeth. Unbeknownst to Alex, Natalie stood outside of the bathroom door and watched her son's performance through the reflection of the bathroom mirror. She observed Alex standing at the bathroom counter for an increased amount of time, and then finally wetting his toothbrush and simply placing it back in its holder. He then reported to his mother that he had completely brushed his teeth. It is believed that Alex did not completely brush his teeth for two reasons: (1) he normally dropped toothpaste all over the bathroom sink trying to place it on the toothbrush, and evidence such as this would indicate failure on his part to his mother, (2) he may not have been able to independently remember the steps to brushing his teeth.

To provide Alex with the cueing he needs while simultaneously allowing him to be more independent with his self-care routine, several visual schedules were implemented at home (Appendices B & C). One visual schedule was made for showering, and another was made for tooth-brushing. During Alex's last session with only minimal verbal cues to read the information on the schedule if the picture was inadequate, Alex followed his visual schedule in order to

complete the entirety of his showering routine independently. Natalie also reported that Alex will now begin the process of taking a shower by himself (e.g., get out his towel, soap, and bath mitt), whereas he used to simply wait for his mother's guidance when she asked him to begin a shower without her. Additionally, Alex is able to independently follow the tooth-brushing schedule in order to fully brush his teeth without constant prompting from his mother.

Bilateral Coordination at Midline and Crossing Midline

Many of the occupations selected for Alex required components of bilateral coordination at his body's midline and/or crossing of his body's midline. For example, as Alex frosted sugar cookies he was told to stabilize each cookie with his left hand while frosting the cookie with his right; the cookie was placed at his body's midline. Pouring was completed in the same fashion, with Alex stabilizing with his left hand and pouring with the right. Zipping, buttoning, and tying shoes required Alex to incorporate bilateral coordination at midline. Additionally, Alex was encouraged several times to take a "break" from therapy by tossing a football back and forth. This required him to cross his body's midline with the throw. Additionally, Alex was rewarded with the game "Mancala" several times, which requires the players to repeatedly cross their body's midline to move small playing pieces around a board (a literature review was completed on the topic of midline crossing and how it effects children's academic performance: to view a presentation compiled on this area, please refer to Appendix D).

Implementation of Compensatory Strategies

An important part of the current case study included the implementation of compensatory strategies. For example, once several compensatory strategies were implemented, Alex's toothbrush/toothpaste goal was quickly met. Prior to start of the home-program, Alex had been stabilizing his toothbrush against his body while applying toothpaste from a small, travel-sized

tube, making the process awkward and difficult. Alex and his mother, Natalie, were instructed to have Alex stabilize his toothbrush against the bathroom counter with his left hand. Alex was then instructed to dispense his toothpaste from a stand-up tube that had been newly provided. This process provided Alex with much more stability and control; thus, no mis-marks of toothpaste occurred on all of the following trials. Another compensation that was implemented included the use of a specially-made bath mitt. Natalie initially expressed concerns regarding Alex's ability to apply liquid soap to a washcloth and properly utilize it while in the shower, considering that the shower in and of itself was overwhelming to him. JRP suggested that bar soap with a contoured curve might be easier for Alex to hold onto. It was also felt that a bath mitt made to fit to the hand would provide more of an element of control than when compared to a floppy washcloth. Thus, a bath mitt was fabricated to fit Alex's needs. A pediatric bath mitt that was thought to be fun and motivating was purchased for Alex. A pouch with a velcro closure was then sewn onto the back of the mitt, allowing a 'holder' for Alex's soap. Alex was then able to secure the bar soap in the pouch of the mitt and use both during the duration of his showers/baths easily.

During the completion of the initial COPM interview, Natalie had expressed concerns regarding Alex's "buttering" abilities. She stated that when Alex completed tasks such as buttering bread or frosting cupcakes, a great deal of the topping would also be spread onto nearby surfaces (such as the countertop or plate that the bread was on). During one of Alex's home therapy sessions, a suggestion was implemented that has greatly improved Alex's accuracy with this task. While beginning the occupation of frosting sugar cookies, a brightly colored piece of paper was placed onto the table where the frosting was to occur. This provided Alex with a greater color contrast between the cookies he was frosting and the background that the cookies were placed upon. Natalie observed Alex's performance, and was pleasantly surprised that Alex

made very few ‘mis-marks’ of the frosting. She stated that later that evening, Alex volunteered to help her butter bread in preparation for making grilled cheese sandwiches. Natalie thought his offer implied that he had felt successful earlier that day frosting cookies and now had a new-found confidence for a once difficult task. Natalie placed the bright-colored paper behind the bread, and discovered that Alex was much more successful with the task than he had been on previous attempts.

A final compensation that was implemented included the use of smaller containers for Alex to pour liquid from. Prior to the start of the home program, Natalie stated that Alex would hold containers of liquid (e.g., a pop bottle) close to his body and flex his trunk in order to pour liquid into a cup. This often resulted in inaccuracy, and a great number of spills. During a home therapy session, a quart-sized container of milk was utilized in the making of “dirt” pudding. Alex was very successful pouring the milk from the container into a measuring cup with only one small spill. Thus, it was suggested to Natalie that the family purchase and re-use smaller container with either handles or ridges for Alex to pour from. The decreased weight of the container would allow Alex to feel more comfortable holding it further from his body, thus increasing the accuracy of his pours.

Creating Opportunities for Effective Communication

Upon beginning Alex’s self-care home program, it was noted that his meltdowns typically occurred when his mother was present and when she was asking him how he felt his performance had been or to perform a specific task right then to be viewed. It was postulated that Alex found this to be upsetting for several reasons. First of all, Alex was noted to be somewhat of a perfectionist: he is driven to complete tasks perfectly, and when something is not perfect, he wants to correct it. Additionally, Alex was noted to thrive on the continuous praise of his parents.

Lastly, Alex appeared to struggle more with performance when he was placed “on-the-spot” and needed to perform difficult tasks while being observed. Combining (1) Alex’s own intrinsic need to perform perfectly (2) with the desire to perform well to please his parents (3) with the need to perform a task under observation, performance that he perceived to be less than perfect resulted in tears and frustration.

The above observations regarding the possible explanation behind Alex’s meltdowns were shared with Natalie. She agreed that Alex did appear to struggle more when she was specifically asking him to perform, or when she or others were watching Alex perform occupations. Thus a system was suggested and implemented in order to avoid meltdowns and allow Alex to practice approaching his mother himself and effectively communicate to her his perceived performance.

First, Natalie agreed to give Alex his own separate working space while completing home therapy, away from herself and Alex’s siblings, as much as was reasonably possible. Second, Natalie agreed to allow Alex to approach her and report on his performance for the day. To facilitate this process, a document was created and laminated to allow Alex to write on it with erasable marker so that it could be re-used. The document contained three sentences with blanks for Alex to fill in as applicable to the particular session. The first sentence stated, “Today, we worked on _____, _____, and _____.” The second sentence stated, “I liked _____ the best.” The third and final sentence stated “_____ was hard for me.”

During the remaining 4 sessions in which Alex’s mother and siblings were less observant of his performance during therapy, Alex did not have any meltdowns, even when certain tasks were difficult for him. Additionally, Alex appeared to be much more comfortable with having time to think about his performance, filling in the respective blanks on the laminated sheet and

presenting this to his mother rather than having to think immediately on the spot about what was completed. Natalie has reported that she is happy with the system and that it is allowing effective communication to occur in situations outside of therapy, such as when Alex works weekly with his tutor.

Rewarding Participation

Considering insight offered by Alex's school therapist, it was known that Alex performed well when a reward was offered for work that he found to be difficult. Additionally, it was known that Alex was able to work well with a delayed type of reward schedule, meaning that he would earn so many "stars" before a reward was offered. In the case of his home-therapy program, a reward schedule was implemented such that Alex would earn one star for each session that he worked hard and did his best in. Once ten stars were earned, Alex would get a prize. This reward schedule was implemented as an attempt to show Alex that his participation in self-care itself was what was being rewarded, not necessarily the quality of his performance, as he was so anxious to perform perfectly in order to please his parents.

Alex performed well with the reward system in place. He would brighten at the prospect of working hard for a star, and the mystery of the surprise prize was motivating for him. It was reiterated to Alex over the course of his home therapy that receiving a star was a reward for working hard to practice, regardless of his perceived performance on the task.

Post-Intervention Evaluation

The PEDI and COPM re-assessment portions were completed April 14, 2010. The results are as follows. While re-assessment via the PEDI shows that Alex is still moderately independent with self-care tasks and still requires a moderate level of caregiver assistance with such, his scores have improved since the initial assessment. For example, Alex received a scaled score of

74.7 out of 100 (with a standard error of 2.1) for self-care as compared to 63.9 at the time of the initial evaluation. Similarly, Alex received a scaled score of 79.5 out of 100 (with a standard error of 5.9) for caregiver assistance with self-care tasks as compared to 71.1 at the time of the initial evaluation (Table 1). These scores indicate that Alex has a greater level of independence since the start of the home program concerning self-care occupations.

Results of the re-assessment of the COPM were positive as well. Alex was rated to have an overall increase from 4 to 8.4 out of 10 for total performance score and 3.2 to 9 out of 10 for total satisfaction score (Table 2). These scores indicate that Natalie believes that Alex's performance in the identified areas has definitely improved, and also that she is more satisfied with Alex's performance in these areas.

Alex made significant gains over the course of his home therapy sessions, meeting all of his goals except for his shoe-tying goal.

First, Alex was able to wash and rinse his whole body and hair while standing in the shower with the use of his picture schedule and bath mitt. He occasionally required minimal verbal prompts to utilize his picture schedule to stay on-task.

Second, Alex was able to engage and zip zippers on donned clothing independently with minimal verbal cues to hold his jacket at the bottom.

Third, Alex was able to fully align and button 100% of buttons on donned shirts. The compensatory strategy of starting to button at the bottom of his shirts was helpful and allowed him to meet this goal.

Fourth, Alex was able to meet his pouring goal with the use of a smaller container with a handle to pour from.

Fifth, Alex met his buttering goal, making few mis-marks provided a color-contrasted background.

Sixth, Alex was able to place toothpaste on his toothbrush with 100% accuracy when stabilizing his toothbrush against the counter and utilizing a stand-up tube of toothpaste.

Lastly, Alex did not fully meet his shoe-tying goal, although progress was made in this area. Several reasons are offered for the lack of total progress. First of all, Alex did not want to place compensatory shoe laces that had been fabricated for him into his shoes. These laces had been threaded with a thin wire, allowing them to hold their shape more easily. Alex was more successful with shoe-tying when practicing with these laces, but less successful when tying his own more “floppy” laces. Second, the task of shoe-tying requires a great deal of fine-motor, bilateral coordination. Tasks requiring these types of skills will always be difficult for Alex considering his stroke and his subsequent tendency to avoid crossing midline. It is felt that with increased practice and intervention focused on bilateral coordination/crossing midline, Alex will be able to continue to improve his skills in this area.

Alex’s mother stated that she was very pleased with the home therapy that was provided to Alex. She reported feeling more relaxed now that Alex is more independent with certain self-care routines, such as showering. She is also happy to have the knowledge of various compensatory strategies that can be utilized in the home to assist Alex.

Overall, Alex has made great gains from the 10 therapy sessions provided to him. It is expected that he will continue to make progress at home concerning independence with self-care

if compensatory strategies are continually implemented and if opportunities for practice are provided. *Discharge Planning*

Upon completion of the home program, discharge planning was completed with Alex's mother, Natalie. It was explained to Natalie that Alex should continue to complete in-school occupational therapy with JRP; Natalie agreed. It was also explained that Alex should continue on with various compensatory strategies implemented in the home program, such as including color contrast behind items he is "buttering," having him pour from small containers with handles, beginning buttoning donned shirts from the bottom, and practicing shoe-tying with the fabricated, rigid laces whenever possible. It was also suggested and agreed upon that Alex should continue to follow the visual schedules implemented for showering and tooth-brushing. Natalie was told that JRP could be consulted with any questions or concerns regarding continuation of elements of the home program following AMW's leave. Natalie understood all of the information presented to her, and felt comfortable with the discharge plan.

Discussion

When comparing the pre- and post-assessments that were completed, results indicate that the interventions and compensatory strategies offered were successful in terms of increasing Alex's overall level of independence with his self-care occupations. Additionally, family communication improved as well, with Alex and Natalie implementing the dry-erase board communication system.

Results also indicate that the FCCA can be an effective one when working with pediatric clients and their families. Without considering the client's parents, the people that "have tremendous insights into their child's abilities," as well as the other members of the child's family, the child may very well fail (Rosenbaum, 1998, p. 3). The child spends most of his or her

time with family, and the child is taught the majority of life lessons by family members.

However, many family members of children with disabilities may not have the resources often provided by therapists, or the energy and time to implement them if they are available. Thus, therapists must be the advocates and initial opportunity providers for their pediatric clients.

Following, therapists must be patient and available to answer any questions that caregivers may have.

This call to advocacy and opportunity provision may not come as easily as providing therapy in the traditional settings (e.g., clinics, hospitals, schools). Therapists must be willing to exit their “comfort zones” and meet families within a natural setting, where real-life occupations make the most sense: the home. This case study proved that great gains can be made within a relatively short period of time when a pediatric client and his family are involved with therapy intervention within the home.

This case study also provides support for the use of the AFR. However, further research should be conducted on this frame of reference, as it is widely used and accepted but not widely documented upon. Various methods commonly utilized by the AFR as used in this case study proved to be very effective, such as positive reinforcement and implementation of visual schedules.

In closing, this case study proved that a FCCA in combination with the AFR were successful in terms of improving the occupational performance of a pediatric client struggling with various self-care tasks. As a result of consistent collaboration and consultation with family members and the client, not only did the client’s occupational performance improve, but communication between family members did as well. Results of this case study offer support for

increased therapy involvement within pediatric client's homes in order to promote the best occupational performance possible.

Acknowledgements

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Table 1

PEDI Scaled Scores at Pre- and Post-Intervention

Domain	Pre-Intervention Scaled Score	Standard Error	Post-Intervention Scaled Score	Standard Error
Self-Care	63.9	1.7	74.7	2.1
Self-Care: Care Giver Assistance	71.1	4.1	79.5	5.9

Table 2

COPM Performance and Satisfaction scores at Pre- and Post-intervention

Occupational Performance Problems	Pre-intervention Performance	Post-intervention Performance	Pre-intervention Satisfaction	Post-intervention Satisfaction
Showering	2	8	2	10
Tying Shoes	2	4	2	5
Brushing Teeth	5	10	4	10
Buttoning	5	10	2	10
Zippering	6	10	6	10

Table 3

BOT-2 Scaled Scores and Age Equivalencies at Initial Testing

Testing Areas Subtests	Percentile Rank	Age Equivalency
Fine Manual Control	7th	
Fine Motor Precision (Right Hand)		5.6—5.7
Fine Motor Precision (Left Hand)		5.10—5.11
Fine Motor Integration		5.4—5.5
Manual Coordination	10th	
Manual Dexterity		4.10—4.11
Upper-Limb Coordination		8.0—8.2
Body Coordination	21st	
Bilateral Coordination		5.6—5.7
Balance		6.0—6.2
Strength and Agility		
Strength (Knee Push-Ups)		5.2—5.3

Appendix A

The occupation chosen for the focus of this occupational synthesis/re-synthesis is that of a shower. Thus, the planned and initial occupational form could be entitled “Bathing while sitting in private home bathtub with occupational therapy student.” Relevant aspects of the planned occupational form included a compensatory shower mitt (made to hold the client’s soap in a sewed-on pocket), a removable shower head, and a bottle of shampoo.

It was predicted that Alex would find meaning and purpose in the planned occupation of showering. For example, showering leads to cleanliness, which is mandated by society. Thus, cleanliness is a “societal norm,” Alex is old enough to understand that it is important to be clean and not “smelly,” and that if you are “smelly,” you will most likely be avoided and/or teased by your peers. As far as purpose is concerned, it was assumed that Alex would have a high level of purpose for showering because his mother greatly wanted him to shower, and Alex was highly motivated to please his mother. Additionally, Alex’s younger siblings were currently showering independently. With Alex being the oldest child, he enjoyed taking charge and leading his siblings; this it was assumed that the area of showering would be no exception.

It was assumed that overall Alex would perform well on the initial showering occupation. It was planned that Alex would not initially take a “true” shower, but that the removable shower head would be placed down against the side of the faucet. This way Alex could be in control of the flow of the water and get used to the feeling of it against his body. It was assumed that Alex would need verbal cues for the following steps of the showering occupation and to stay on-task. As far as compensation, it was assumed that Alex would utilize the shower mitt and removable shower head provided to aid him with the showering occupation. As far as adaptations, it was

assumed that Alex would have less anxiety concerning showering and slightly more confidence for later trials of this occupation. No changes were made in the actual occupational form.

The actual occupational performance included the following. Alex required a verbal cue to obtain a towel and place it on the counter. The occupational therapy student then retrieved the removable shower head from the high base and placed it against the side of the tub faucet. Alex independently turned the water on and rinsed himself off, exclaiming “Ahh, the water feels good!” After several minutes of rinsing, Alex was prompted by being asked “What do you need to do next, Alex?” He then said, “Oh yeah! I need to put the soap in my bath mitt.” He struggled with sliding the soap into the mitt; the occupational therapy student demonstrated the technique to him as he watched. Throughout the “shower,” Alex required moderate verbal cuing to stay on-task (e.g., “What comes next Alex?”). He also required verbal cuing to remain standing throughout most of the duration of the shower, as he prefers sitting down. Lastly, he required verbal cuing to count the duration of time he was pouring out shampoo (e.g., “One, two, stop!”). With verbal cuing, Alex independently bathed and rinsed his entire body, including his hair. At the end of the “shower,” Alex was rewarded by being able to take a bath and play in the water.

The inferred meanings and purposes are typical to that of a young boy encountering the occupational form in which Alex did. For example, Alex recognized all of the physical aspects of the occupational form correctly, such as the bath mitt, shower head, shampoo and soap with their respective use. Alex also recognized the occupational therapy student as being a part of his form, and he verbally interacted with her throughout the duration of the occupation. It is inferred that Alex applied meaning to the occupation because showering is becoming more of the norm for children his age; also, Alex understands that his mother wants him to take showers, and he is

motivated to please his mother. As far as purpose, it is inferred that Alex had a high level of purpose during the occupation based on his engagement with the occupational therapy student and staying focused on the task until it was completed. Additionally, Alex was motivated towards receiving the reward of a bath at the end of his shower.

Assessment information gained through this initial showering occupation concluded that Alex felt more comfortable with taking a shower when he was in control of the flow of water with the removable shower head. Additionally, it was noted that Alex was successful with the showering occupation as long as he was provided cues to stay on-track.

Several features of the occupational form were obviously eliciting therapeutic compensation. These items were the fabricated bath mitt and the removable shower head. The bath mitt allowed Alex to have fewer items to “juggle” at one time, while the removable shower head allowed Alex to feel in control of the showering occupation.

For the next showering occupation, the compensatory strategy of a visual schedule was implemented. It was predicted that Alex would apply meaning to the visual schedule as it included not only text for him to read, but also pictures of himself completing the various steps of the showering occupation. It was also predicted that Alex would have a high level of purpose concerning the visual schedule considering the pictures of him on it. It was predicted that Alex would demonstrate a higher level of independence in showering with implementation of the visual schedule, as it would provide the “cuing” he needed to stay on-task.

When presented with the visual showering schedule prior to the start of the occupation, Alex was very excited. He grinned widely and stated, “Hey, that’s me on there!” He then ran off

to his mother to show her the schedule. He said, "Hey look Mom, it's me in all of these pictures!" He then read several of the showering steps aloud to her from his schedule. When she asked him if he thought the schedule would help him to be more successful in the shower, he said yes. After the visual schedule was secured inside of the shower, Alex took a shower.

The removable shower head was again removed by the occupational therapy student and placed against the tub faucet. Alex referenced his visual schedule, and independently retrieved a towel from the closet and placed it on the counter. He then retrieved his bath mitt and soap, and utilized the visual schedule and the previous demonstration by the occupational therapy student to correctly place the soap into the holder. He then got into the bathtub and followed the visual schedule to turn on the water, wash his legs and feet while sitting at the edge of the tub, wash and rinse the rest of his body, and wash and rinse his hair (when pouring out the shampoo, Alex counted aloud without being prompted, "One, two, stop....see, I remembered!"). Alex required only minimal cuing at times to re-orient himself to his schedule: otherwise he was able to utilize it to complete his shower independently.

The inferred meanings and purposes for this occupation are generally the same as for the previous showering occupation. However, it is felt that Alex had a more increased level of meaning and purpose following the implementation of the visual schedule. Assessment information concluded that Alex had an increased level of independence with implementation of the schedule as it provided him with the cues he needed to be able to stay on-task. Compensations for this occupation are the same as were previously listed, with admission of the visual schedule. An adaptation that was felt to be made with completion of this occupation included having a greater level of independence when taking a shower.

Appendix B

1. Get **towel**, put on the counter



2. Put **soap in bath mitt**



3. Get **bath mitt wet: rub** with hand for soap suds



4. **Sit** at edge of tub: wash **legs and feet**



5. Wash **belly and chest**



6. Wash **arms, arm pits, and hands**



7. Wash **face**



8. Rinse off body



9. Get **hair wet**



10. Put **shampoo** in hands....**count, "1, 2"**



11. **Wash** front, sides, and back of **head**



12. Rinse hair



13. Pull soap out of mitt: put **soap on shelf**



14. Turn **water off**



Appendix C

1. Get toothbrush and toothpaste



2. Toothpaste on toothbrush



3. Get toothbrush wet



4. Brush teeth then spit



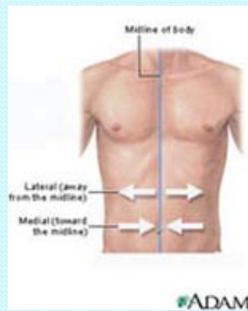
5. Put toothbrush and toothpaste away



Appendix D

Midline and why it matters

Anna M. Wearsch



Outline

- Definition of midline & midline crossing
- Neurology behind midline crossing
- Why midline crossing matters

Midline and Midline Crossing

- Midline: “An imaginary line that divides the body into right and left halves” (Mosby’s Medical Dictionary, 2009)
- Midline crossing: “Manual midline crossing occurs when an individual, extending one hand to grasp an object, reaches across the body midline” (Carlier, Doyen and Lamard, 2006)



Neurology behind midline crossing

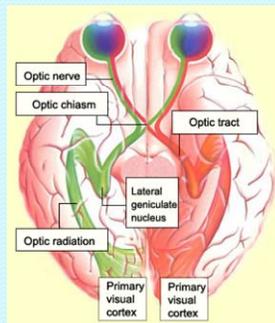
- How the body is “hard-wired” to communicate
 - To have effective, functional movement, both ½’s of body need to work together
- Crossing of fibers throughout our entire bodies
 - Starting in the brain



- The right side of the brain controls the left side of the body, and vice versa
- “Corpus Collosum” = bridge to allow both sides to communicate

Neurology behind midline

- Why do fibers need to cross sides of the body?
 - What started it?



(Cajal, 1898, as cited in Vulliamaz, Raineteau, and Jabaudon, 2005)

- Optic fibers that cross at the “optic chiasm”
- Cross in order to allow both sides of brain to have a complete picture
- Since optic fibers cross, “tactile” pathways should too
- Motor pathways need to cross back the other way

Neurology behind midline

- Corticospinal Tract
 - A “bundle” of over 1 million nerve fibers
 - Largest, most important descending tract
(Gondim and Thomas, 2009)
 - Control “fine movements” of hands
 - **Handwriting!**
 - Tying/buttoning/zippping
 - Playing the piano/knitting/etc.

(Vulliamaz, Raineteau, and Jabaudon, 2005)



Development of Neurology

- Corticospinal Tract
 - Develops late in the womb
 - Ongoing development within 1st year of life
- Corpus Collosum
 - Completely developed at age of 10
 - Until fully developed, may see “mirror movements” in younger children

(Vulliamaz, Rainteau, and Jabaudon, 2005)

So What?

- Study showed that # of midline crossings  with age
 - Significant differences found between 3-4 year olds and 8-10 year olds
 - This correlates with time frame for corpus collosum
- Something to consider...
 - Younger children will have greater difficulty with activities requiring a lot of midline crossing (e.g., **handwriting, reading**, music, sports)
 - You may see more “mirror movements”
 - Has to do with brain development, not lack of trying

(Carlier, Doyen, and Lamard, 2006)

Indicators

- Turning paper perpendicular to body to write
- Writing down one side of paper
- Sitting sideways in chair
- Sliding over to reach something with same-side hand rather than reaching across (ex: air hockey)
- Reading words on one side of page only
- Difficulties with games, such as ping-pong/tennis

How it affects academics

- Difficulties...
 - Reading left to right
 - Writing left to right
 - Justifying to left
 - Indenting
 - Locating things in text
 - Cutting
 - Typing
 - Spelling



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