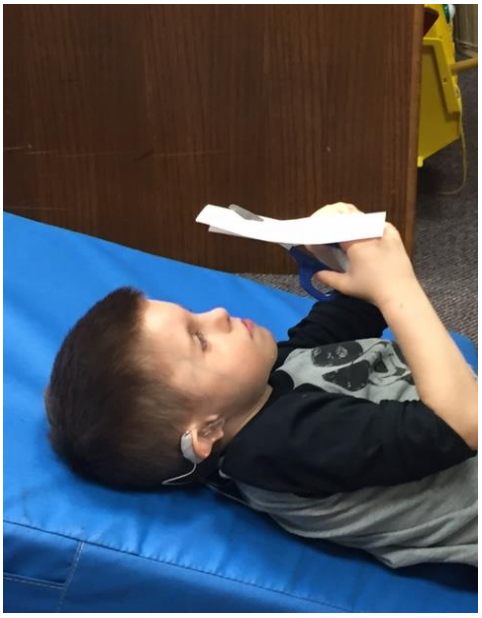
# Positioning Interventions to Facilitate Fine Motor Skills in Children with CHARGE Syndrome and/or Deafblindness

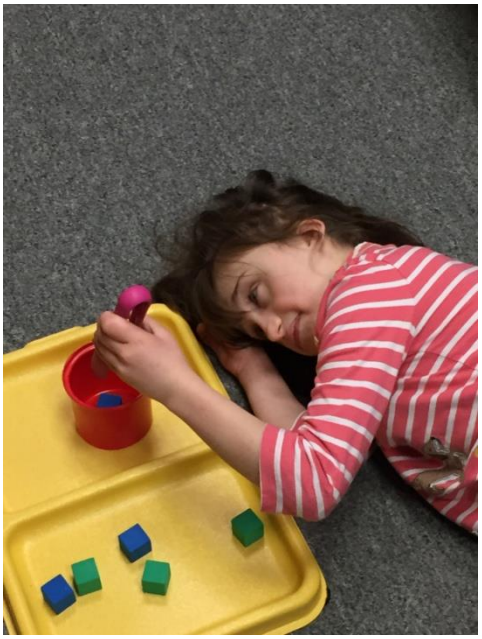
**Samantha Kublin, Sarah Bis, Diane Smith, and Sarah Maust**

In the school setting, most activities are presented to children while seated at a desk or at tabletop (Aminian, Hinckson, & Stewart, 2015). Of the numerous professionals and related service providers on a child's educational team, an occupational therapist is uniquely qualified to assess the sensory and motor demands of a given task and/or the environment in which the task is presented (American Occupational Therapy Association [AOTA], 2014). David Brown (2006; 2007), deafblindness educational specialist, explains that challenges in tactile, vestibular, and proprioceptive senses are common for children with deafblindness and/or CHARGE syndrome. Proprioception is defined as the way we can feel where our body parts are in relation to each other without having to touch or look at them (Brown, 2006). The vestibular sense informs us of the position of our head in relation to gravity, enabling us to feel oriented in space (Brown, 2007). Deficits in these sensory systems impact a child's abilities to participate in school tasks. Individuals with CHARGE syndrome have an impaired vestibular system due to the absence or malfunction of the semicircular canals in the inner ear as well as an impaired proprioceptive system due to low muscle tone. Both contribute to impaired balance and postural insecurity for people with CHARGE syndrome (Brown, 2003). Due to these sensory deficits and low muscle tone, David Brown (2003) suggests that there is a marked preference for children with CHARGE syndrome to assume a supine or a side-lying position. This is in line with an

Natalie drumming in side-lying position



Jacob cutting with scissors in supine position



Grace playing with tongs in side-lying

occupational therapist's understanding of the child's need for a stable base of support and postural control before he or she is able to accurately perform fine and visual motor tasks utilizing his or her hands and eyes together (Case-Smith, Fisher, &, Bauer, 1989).

In the field of education of children with CHARGE syndrome, one common suggestion is to incorporate frequent sensory breaks throughout the school day (Stelzer, n.d.). During these sensory breaks, children may assume a variety of positions on the floor that reduce the demands of their postural muscles and their need to process vestibular and proprioceptive information. Most frequently, all educational demands are removed from the child during a sensory break (Stelzer, n.d.). Sitting in a beanbag chair or having contact with the floor provides increased tactile and proprioceptive information to their body to help them better understand where their body is in space (Brown, 2006). Having educated a large number of children with CHARGE

syndrome, over time, staff in the Deafblind Program at Perkins School for the Blind[1] have asked the question “Can a child complete functional tasks in this position? Can working in positions on the floor that provide an increased proprioceptive input facilitate fine motor skills?”

**Three Positioning Interventions**

Two positions that provide increased proprioceptive sensory input to the body are side-lying and supine. A side-lying position is defined as placing a child on his/her side with a support on his/her back. A supine position is defined as lying on one’s back (Masin & Nicholson, 1990). These positions provide increased proprioceptive sensory input to a child’s entire side or back, allowing him/her to feel more organized and physically stable, reducing the postural demands of working against gravity. Both side-lying and supine positions also reduce the need to use postural control of the head and neck to stabilize vision. When the child does not need to use his/her arms to support the upright position of their trunk, neck, and head, he/she has the freedom of movement to use his or her hands and fingers to engage in fine motor activity. A side-lying position facilitates movement across midline, for example when a child moves his/her left hand across his/her body to the right side. Therefore, side-lying and supine can be helpful positions to facilitate fine motor skills for children who have insults to their sensory systems and/or who have low muscle tone.

The purpose of this research study was to answer the questions posed by the occupational therapists at Perkins School for the Blind and determine the effectiveness of positioning interventions in improving fine motor skills for school-aged children with CHARGE syndrome and/or deafblindness. The increase in fine motor skills can assist

[1] Perkins School for the Blind (www.perkins.org) is a large corporate member of DbI

children with CHARGE syndrome and/or deafblindness to achieve optimal participation in school, self-care skills, and play.

**Clinical Findings**

The participants in the study were seven students with deafblindness with residual vision, four of whom had CHARGE syndrome. All of the students had specific objectives related to fine motor skills in their Individualized Education Program (IEP). The students were ages four to thirteen years old enrolled in the Deafblind Program at Perkins School for the Blind. The students participated in thirty-minute occupational therapy sessions focusing on fine motor skills in all three positions twice a week for an average of ten weeks. Data were recorded on the following skills:

- Motor action that occurs on one side of the body
- Crossing the midline of the body
- Use of one hand
- Bilateral coordination, with both hands performing the same function
- Bilateral coordination, with each hand performing a separate function
- Use of residual vision during the motor task
- Engagement in self-stimulatory or other behavior that interferes with use of the hands

In addition, data were collected on the student's specific IEP objectives related to fine motor skills. The data collection methods were based on items from the Peabody Developmental Motor Scales (PDMS-2) and clinical observation (Folio & Fewell, 2000).

Measurable trends were observed when comparing the data recorded prior to the intervention and post intervention when the students were willing and able to participate. Overall, stability or progression of all fine motor skills was observed, with no regression of skills seen. Progression was defined as an increased frequency of engaging in a more advanced skill and a decreased frequency of engaging in an easier skill.

Crossing the midline of the body while performing motor action is a more advanced skill than performing action on only one side of the body. Engaging in any fine motor task with two hands (bilateral coordination) rather than one is also a more advanced skill. An example of bilateral coordination with both hands performing the same function would be using two hands to hold onto a ball when placing it into a container. An example of bilateral coordination with each hand performing a separate function would be using one hand to hold onto the ball and the other hand to hold on to the container. One hand is manipulating the ball while the other is stabilizing the container. The latter of the two examples is a more advanced skill.

The specific number of students who improved in each skill in each position can be seen in Table 1. This table illustrates the number of participants out of seven who improved in each particular fine motor skill and in each position. The cells highlighted indicate the fine motor skills with the most improvement. Specifically, six out of the seven participants had improvements in using their residual vision during the motor action to complete a fine motor task when seated in a chair at a table or in a side-lying position.

**Table 1: Improvements in Fine Motor Skills**

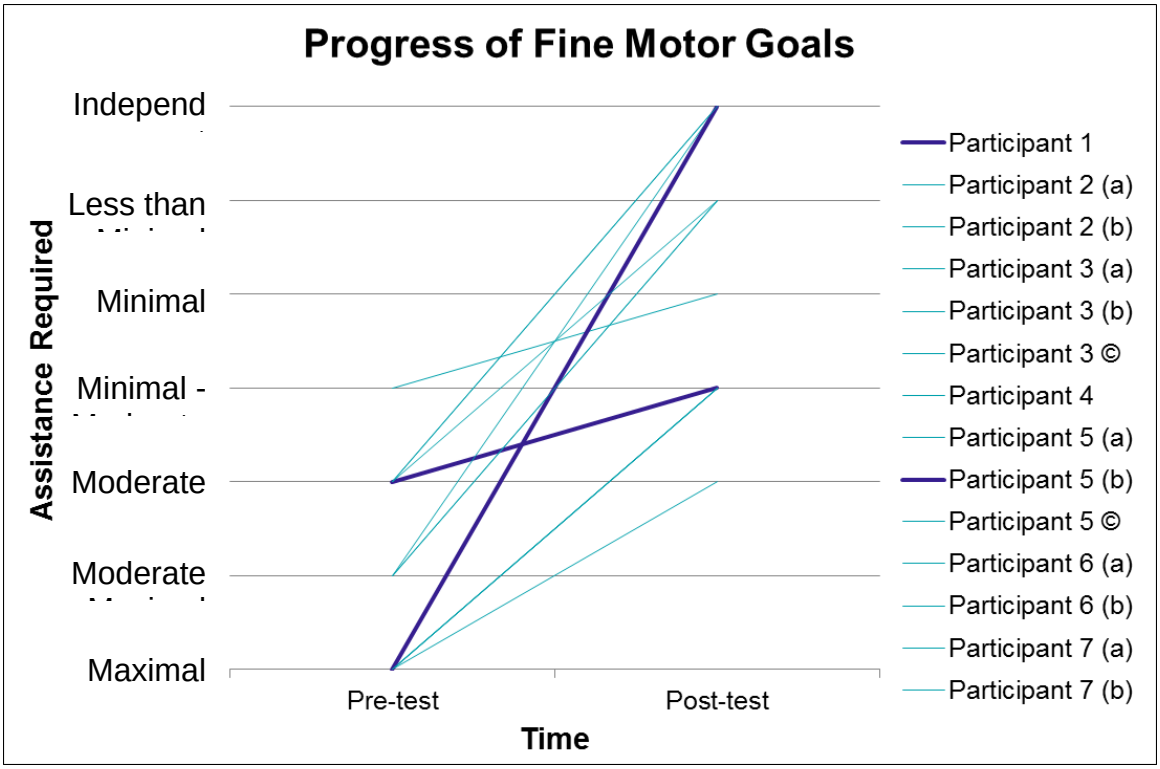
| Position | Same side action | Cross midline | Use one hand | Use two hands, same action | Use two hands, different actions | Use vision during motor action | Total |
|---|---|---|---|---|---|---|---|
| **Tabletop** | 0 | 4 | 2 | 2 | 5 | 6 | 19 |
| **Supine** | 0 | 2 | 4 | 0 | 4 | 5 | 17 |
| **Sidelying** | 0 | 4 | 4 | 0 | 5 | 6 | 23 |

When comparing the three different positions, the participants' fine motor skills improved most in the side-lying position, followed by seated at a tabletop, and then a supine position. Sitting at a table was most frequently associated with increased use of residual vision during the motor action whereas sitting in a side-lying or supine position was most frequently associated with increases in the participant's ability to use two hands to perform different actions as well as use residual vision during the motor action. No clear trends were seen in engagement of self-stimulatory behavior during the positioning intervention, likely due to a number of external factors.

Progression on all fine motor goals for each participant was also observed. Progress was defined as requiring less physical assistance to complete a fine motor task. However, the magnitude of progress differed for every student. Some students showed minimal progress while others exhibited more notable progress. These trends can be seen in Figure 1. For example, one student progressed from requiring moderate physical assistance (assistance for 45-59% of the task) to place items into a container prior to the positioning intervention to requiring minimal to moderate physical assistance

(assistance for 30-44% of the task) at the post-test treatment session. Another student progressed from requiring maximal physical assistance (assistance for 75-99% of the task) to put on two socks to completing this task independently by the end of the research study. The highlighted lines in Figure 1 represent these two examples to illustrate the difference in magnitude of progress among participants.

**Figure 1**




This graph illustrates the amount of assistance required to complete a fine motor goal at the pre-test compared to the post-test treatment session. The following are explanations of the physical assistance required: Maximal =75-99%, Moderate-maximal = 60-74%, Moderate = 45-59%, Minimal-moderate = 30-44%, Minimal = 15-29%, Less than minimal = 1-14%, Independent = 0%. The highlights lines indicate the two examples mentioned in the article

## Conclusions

The results of this study answer the question that working in positions on the floor that provide an increased proprioceptive input *can* facilitate fine motor skills. Overall progress in fine motor skills was seen for each participant in all three of the positions indicating that fine motor skills can be addressed in multiple positions. Having a student practice fine motor tasks in a position that provides increased proprioceptive sensory input to his/her body may assist him/her in utilizing their hands and eyes together in a more productive manner.

However, it is important to keep in mind that the amount of progress achieved by each student is influenced by multiple factors, including the difficulty of the fine motor task, the amount of exposure and practice with the task, the amount of exposure and practice in the position, and motivation to complete the task. Below are some general recommendations to assist in using this intervention with a student or child with deafblindness and/or CHARGE syndrome.

## Recommendations

- Provide the child with opportunities to change positions. Take note of which position the child prefers most and which is most functional for the child. Provide numerous opportunities throughout the day for the child to engage in fine motor tasks in that optimal position.

- Establish a consistent routine within therapy or classroom sessions. Create a specific area in the classroom or home where the child can assume specific positions to help the child anticipate expectations.
- Observe and endeavor to understand the child's sensory seeking behaviors. Consulting with a trained professional, such as an occupational therapist, is recommended.

## References


American Occupational Therapy Association. (2014). Occupational therapy practice framework: Domain & process, 3rd edition. *American Journal of Occupational Therapy*, (S1), 1.

Aminian, S., Hinckson, E. A., & Stewart, T. (2015). Modifying the classroom environment to increase standing and reduce sitting. *Building Research and Information, 43*(5), 631-645.

Brown, D. (2003). *CHARGE network meeting: Some behavioral implications of sensory difficulties found in children with CHARGE Syndrome.* Retrieved from http://www.deafblindinternational.org/cause_conf10.html

Brown, D. (2006). The forgotten sense- proprioception. *Deafblind International Review,* 20-24. Retrieved from http://www.caoms.org/images/2010/TheForgottenSense-Proprioception.pdf

Brown, D. (2007). The vestibular sense. *Deafblind International Review*, 17-22. Retrieved from: http://files.cadbs.org/2000003539f7fca079e/2_vestibular_dbrown.pdf

Case-Smith, J., Fisher, A., & Bauer, D. (1989). An analysis of the relationship between proximal and distal motor control. *American Journal of Occupational Therapy, 43*, 657-662.

Folio, M. R., & Fewell, R. R. (2000). *Peabody Developmental Motor Scales* (2nd ed.). Austin, TX: PRO-ED.

Masin, H., & Nicholson, C. (1990). *A series for caregivers of infants and toddlers, motor development: What you need to know.* Florida: Florida Department of Education. Retrieved from: http://phstwlp2.partners.org:2492/fulltext/ED403682.pdf

Stelzer, S. (n.d.). *CHARGE syndrome: Teaching strategies for children.* Retrieved from http://www.perkinselearning.org/videos/webcast/charge-syndrome-teaching-strategies-children#chapter5

For additional information, contact Samantha Kublin, OTD (SKublin@mghihp.edu)

.