Differential Performance of Children With and Without Cerebral Palsy on Graphomotor Cognitive Processing Speed Measures

by

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Abstract

Individuals with cerebral palsy (CP) are at risk for low performance on traditional measures of cognitive processing speed (PS) due to motor impairments rather than slowed PS. Two common measures of PS are Coding (Cd), utilizing complex symbolic writing, and Symbol Search (Ss), utilizing simpler cancelation. The primary aim was to determine if children with and without CP demonstrate differential performance on these tasks, depending on graphomotor complexity. A sample of 139 children (43 CP) were administered the Cd and Ss tasks and demographic measures. Group was found to be a significant predictor of the difference in performance between the PS tasks independent of intellect, with the CP group achieving higher Ss scaled scores. The measure of dexterity was not a significant predictor. This study highlights both the need to be cautious when interpreting PS measures in the CP population and the need for more universally accessible neuropsychological assessment methods.

Differential Performance of Children With and Without Cerebral Palsy on Graphomotor Cognitive Processing Speed Measures

Cerebral Palsy (CP) is one of the most common disabling conditions of childhood, affecting approximately two in every 1,000 children world-wide (Blair & Watson, 2006; Odding, Roebroeck, & Stam, 2006). Classified primarily as disorders of movement, the CPs present in many different forms, each originating from non-progressive pre, peri, or early postnatal brain damage (Rosenbaum et al., 2007). As part of the diagnostic profile, symptoms must be *non-progressive*, and must result from *early* brain damage marked by movement and/or postural impairments (Rosenbaum et al., 2007). In addition to the non-progressive nature and central motor features that define this condition, those with CP also have an increased risk for comorbidities such as cognitive and social difficulties, seizures, and Attention-Deficit/Hyperactivity Disorder (ADHD) (Schenker, Coster, & Parush, 2005; Singhi, Jagirdar, Khandelwal, & Malhi, 2003; Venkateswaran & Shevell, 2008). Due to the clinical variability observed with the physical manifestations of CP, this variability of cognitive comorbidities is not surprising.

Cerebral Palsy: Classification

Because CP is such a heterogeneous condition, affected individuals can differ in many aspects of their diagnosis, including clinical presentation, etiology, neuropathology, and comorbid impairments (Warschausky, White, & Tubbergen, 2010). Since there are so many factors taken into consideration when diagnosing, treating, and researching CP, multiple classification systems based on these attributes exist. One example of these systems is the Swedish System. This system is based solely on describing the nature of the motor dysfunction and thus classifies the CPs based on type of movement and involved body parts (d'Avignon,

Bille, Hagberg & Olow, 1960; Hagberg, Hagberg & Olow, 1975). The four different subtypes of movement in the Swedish system include spastic (abnormal increase in muscle tone), dyskinetic (no muscle control), ataxic (abnormal decrease in muscle tone), and mixed (more than one type). The terms identifying different body parts involved (primarily arms and legs) include hemiplegia (one side of body), digplegia (both sides), and quadriplegia (all limbs). Although CP comes in many forms, according to the Center for Disease Control and Prevention (CDC; 2004), the majority of those with CP (about 70 to 80%) have the spastic form.

Cerebral Palsy: Risk Factors, Etiologies, and Brain Damage

There are many risk factors associated with CP. In industrialized nations, the most common of these factors include prematurity, low birth weight, and multiples birth (Odding et al., 2006; Warschausky et al., 2010). In addition, as it is an incredibly heterogeneous disorder, a varying number of brain lesions can result in the physical manifestations of CP. These brain lesions are commonly caused by infections, cerebrovascular accidents, head injuries, asphyxiation (Blair & Watson, 2006), and periventricular leukomalacia, and fall in to four main groups: white matter damage, cortical and subcortical lesions, brain malformations, and postnatal injuries (Odding et al., 2006). Overall, there is considerable heterogeneity in both etiology and physical and cognitive presentation associated with CP.

Neuropsychological Profile of Persons with Cerebral Palsy

Although the diagnosis of CP does not formally include a cognitive component, because it is a condition caused by neurological insult(s), there are commonly cognitive aspects of the disorder. In fact, there are a variety of cognitive factors that can be affected in association with a CP diagnosis, including language and verbal abilities, visual-perceptual and visual spatial abilities, learning and memory, executive functioning and attention (Straub & Obrzut, 2009).

While the degree to which these abilities are impaired depends on the etiology and nature of the lesion, as well as its physical manifestation, there are some general trends seen in the neuropsychological profiles of children with CP. In addition to fine and gross motor deficits inherent in a CP diagnosis, relative to typically developing (TD) peers, individuals with CP have an increased risk for perceptual deficits and phonological skill deficits (Straub & Obrzut, 2009). They also demonstrate increased risk for difficulties in communication and language use, sensory deficits, deficits in visual perceptual abilities, deficits in visual spatial abilities, learning problems, short-term memory deficits, and slower learning over repeated trials (Straub & Obrzut, 2009). Lastly, executive functioning, strategy generation, slower response time, more intrusions, inhibition and attention difficulties, and deficits in executive function are also shown in those with CP. While general trends have been presented in the literature, there is a great deal of work to be done in this area to further examine the presence of these cognitive impairments in persons with CP, as well as the methods used to evaluate them.

Neuropsychological Methods: Estimating Cognitive Function in the Clinical Setting

The cognitive functions discussed above are largely measured using neuropsychological testing. Clinically, this type of testing is typically used to assess learning or behavior disorders, with these assessments employing a battery of surveys, interviews, paper-and-pencil testing, testing involving handling of manipulatives, and computer testing. More specifically, these tests are used to evaluate general intellect, achievement skills, executive skills, attention, learning and memory, verbal reasoning, visual-perceptual reasoning, behavioral and emotional functioning, social skills, and motor coordination. While these assessments are well-established methods to detect learning and behavioral disorders in children, there is a concern regarding their ability to accurately capture the cognitive functions they are intended to in individuals with CP; this

concern is primarily due to the speeded motor and speech demands inherent in most of these tasks (Warschausky et al., 2010).

Cerebral Palsy: Measure of Motor Function

Because CP is primarily defined as a movement disorder, two measures are frequently employed to evaluate gross and fine motor functioning in this population: The Gross Motor Function Classification System (GMFCS) and the Manual Ability Classification System (MACS). The GMFCS (see Appendix A) uses five levels to classify the *gross* motor functioning of individuals with CP, with level one indicating the gross motor function of a TD individual and level five indicating very limited gross motor ability (Palisano et al., 1997). In contrast, the MACS (see Appendix A) uses five levels to assess and categorize *fine* motor functioning (i.e. manual dexterity), with level one being comparable to that of a TD individual and five being very limited fine motor ability (Eliasson et al., 2006). Both systems offer an ordinal assessment of functional motor abilities in individuals with CP.

Processing Speed Measures in the Cerebral Palsy Population

The concern regarding the negative impact of impaired motor function on accurately capturing cognitive constructs, through neuropsychological measures, is particularly prevalent in measures of processing speed (PS). PS is defined as the speed at which an individual can process basic information (i.e. thinking speed) and has been shown to be correlated (r = -.29) with "g", or general intelligence (Sheppard & Vernon, 2008); more specifically, lower required processing times are correlated with higher intellectual ability. PS is also associated with other, more psychosocial risks. For instance, if a child processes information more slowly than his or her TD peers, the child may also have difficulty responding to his or her teachers or peers in an appropriate time period, potentially having adverse effects on that child's learning and social

experiences. PS tasks are administered in association with intellectual testing for children in the clinical setting and nearly all of them have an inherent speeded or timed motor or speech demand. Thus, the concern that arises is that, in addition to capturing an individual's PS, these measures also have the unintended effect of reflecting deficits in individuals who have slowed speech or movement.

Among the most commonly administered measures of PS are the Symbol Search (Ss) and Coding (Cd) tasks from the Wechsler Intelligence Scale for Children-IV (WISC-IV) (Wechsler, 2003). While both subtests are paper-pencil measures of PS with a speeded graphomotor demand, it is important to note that they differ greatly in the *level* of this demand; a quality that may allow them to reveal how differences in graphomotor demand affect the outcome of PS tasks, particularly in individuals with CP who may be more susceptible to these differences.

In the Ss task (see Figure 1A for sample and Appendix A for complete task), children are shown two symbols and they must decide if either of these symbols appear in the group of symbols to the right. Once they make the decision, they mark a "yes" or "no" box. Scores are calculated by subtracting the number of inaccurate trials from the number of accurate of trials completed in a 120s time period. In the Cd task (see Figure 1B for sample and Appendix A for complete task), children are given a key presenting a set of numbers, in numerical order, matched with corresponding symbols for each number. Below this key, they are presented with a non-ordinal string of numbers without their associated symbols, and are required to reproduce the appropriate symbols below each given number in a 120s time period. Scores are calculated as the number of correct trials completed. The Cd and Ss tasks are both intended to measure the same underlying construct, cognitive processing speed (PS), and are typically combined to calculate a child's composite PS score as part of the WISC- IV (Wechsler, 2003).

Accuracy of Processing Speed Measures in Individuals with Cerebral Palsy

Importantly, to date, the bulk of clinical practice uses the Cd and Ss tasks to assess PS in children with CP. However, while both Cd and Ss subtests are structured to measure a common, underlying construct (cognitive PS), the efficacy of these measures to similarly evaluate PS in individuals with motor dysfunction, such as those with CP, has not been established. Furthermore, these tasks differ in motor demand; the Cd task has a greater graphomotor demand than the Ss task, as the Ss task is simply a gross cancellation task, whereas the Cd task is a more complex symbolic reproduction task. Due to the motor dysfunction inherent in a diagnosis of CP, this unequal motor demand could be expected to produce differential performance between these two measures, which are intended to measure the same construct.

Consequences of a Biased Measure: The Effects of an Underestimate of PS

While a correct estimate of a child's PS can be helpful in ensuring appropriate access to education and any required education supports, a biased estimate of PS can result in an inaccurate determination of support needs for a child in the educational setting. This is particularly relevant as an evaluation by a school psychologist to determine a child's special education needs and services often utilizes the Cd and Ss tasks. Notably, many children with fine motor dysfunction are able to complete these measures functionally, though there is no mechanism to ensure that the performance is a valid estimate of cognitive PS. When a child's cognitive abilities are inappropriately measured, the student's Individualized Education Plan (IEP), or the legal binding document that allows children access to special services and classroom modifications and accommodations based on their condition (The Individuals with Disabilities Education Improvement Act of 2004), is not accurately representative of the student's needs. Thus, an inaccurate IEP can lead to inappropriate educational support.

Particularly when it reflects an *under*estimation in ability, such as PS, an inaccurate IEP can lead a student to be denied equal access to mainstream, general education material and instruction. Furthermore, the use of an inappropriate measure can also lead to inappropriate and costly services and assistive technologies for a student in the absence of a true need.

Hypothesis

It is important to ensure that the current Cd and Ss tasks administered capture the intended construct of cognitive PS. Although designed to be highly correlated measures of PS, there are differences in the demands of these tasks. Because CP is the consequence of brain injury, the presence of associated cognitive deficits is not surprising. However, these deficits may be related to differential performance between these measures of PS relative to TD peers. Further, an inherent motor dysfunction in children with CP coupled with the unequal motor demand in these tasks suggests that if such a difference is present, it is likely strongly predicted by dexterity deficits. In order to assess the appropriateness of current PS measurements in this population, an archival data set with information on PS measures (Cd and Ss), dexterity (measured by MACS levels), and other demographic variables of children with CP and TD children was used. It was hypothesized that the CP group would show a difference in performance on the Ss task versus the Cd task (scaled scores). Furthermore, the CP group was expected to achieve a higher scaled score on the Ss task relative to their scaled score on the Cd task, due to the less involved graphomotor demands (i.e. simple cancelation compared to symbolic writing); it was anticipated that this difference would be predicted by group (CP versus TD) and dexterity (MACS).

Method

The present study utilized an archival data that was collected as part of a larger study that took place at in the Adapted Cognitive Assessment Laboratory (ACAL) at the University of Michigan Health System (UMHS) Department of Physical Medicine and Rehabilitation. The primary aim of this larger study was to look at the psychometrics of modified accessible assessment strategies for children with Cerebral Palsy, specifically modification of an Inspection Time (IT) task. The methods for this data collection are discussed below.

Participants

Recruitment. Participant recruitment was carried out in accordance with the methods already approved by the Institutional Review Board of the University of Michigan. There were three different methods of recruitment in this study: parents were either approached at routine clinic visits at the University of Michigan Department of Physical Medicine and Rehabilitation, or heard about the study by word of mouth or through public postings (see Appendix B for templates).

Screening. Those who were interested in participating contacted the ACAL. Following this contact, ACAL research assistants completed a phone intake (see Appendix B for form used) to ensure participants fit the study inclusion and exclusion criteria (see Table 1). It was required that all participants provide informed assent and their parents informed consent, and that participants be between ages 8 and 16, as this is the age range necessary for the versions of the Cd and Ss measures used. In addition, participants with CP were also required to have a previously documented medical diagnosis of CP, the ability to communicate a dichotomous choice response (as measured a raw score of 12 or greater on the Dichotomous Choice Screen; see Appendix B for form used), the ability to communicate orally, and a classification of level I,

II, or III on the Gross Motor Functional Classification Scale (GMFCS; see Appendix A). In the current study it was necessary to include only relatively high motor functioning children with CP from the larger dataset, as lower motor functioning children did not have the functional ability to manipulate a pencil to complete the graphomotor Cd and Ss tasks. Broader exclusion criteria for the larger study included inconsistent dichotomous responses, hearing impairments and/or visual impairments which precluded hearing/seeing instructions, any medical or psychiatric condition, unstable or frequently changing medications that may affect cognitive function, and history of an acquired brain injury (outside of that causing the child's CP). Participants were also excluded if their primary caregivers presented with a medical or psychiatric condition that would interfere with their participation. Following the screening of participants, parents set up appointments to come in to the UMHS Department of Physical Medicine and Rehabilitation ACAL to participate in the study.

Consent. All participants provided informed consent (from the primary caregiver) and assent (from the child) for participation in this study (see Appendix C for consent and assent forms). During this process, both child and primary caregiver were brought in to a private room where they were presented with a written consent describing the details of the study, including the name, sponsors, names and contact information for the Principal Investigator and Co-Investigators, populations involved, purpose of the study, risks and benefits of the study, and overall description of the tasks involved. In addition to this written presentation, the consent information was also presented orally by a trained research assistant and discussed thoroughly before informed consent by the parent was given. A similar, simpler process was followed for assent of the child, including a list of specific questions which were asked to each child. All participants were informed before consenting, in both written and verbal form that they were not

obligated to participate and could stop their participation at any time for any reason.

Sample. A total of 139 children (43 children with CP and 96 TD children) ages 8-16 were pulled from the archive for inclusion in the current study. Please see Tables 2a and 2b for key demographic information, including an estimate of intellect, SES, gestation, gender, race, functional levels, and classification of CP. Intellect was estimated using the Peabody Picture Vocabulary Test-III (PPVT-III; Dunn & Dunn, 1997; see Appendix A for sample page) and SES was calculated by the Hollingshead (1975) method, taking into account the education level and employment of the child's mother and father. There were missing data for three participants in the TD group for SES (N_{TD} = 93), as well as eight participants in the TD group and two in the CP group for gestation (N_{TD} = 88, N_{CP}= 41). Three parents from the TD group responded with levels inconsistent with their child's functional level for GMFCS (gross function) and Expressive Production Rating Scale (ExPRS; communication), as directly observed by the research staff. The research coordinator attempted to contact these parents for clarification, but was unable to reach them (due to disconnected phone line or no return phone call). Thus, participants were still included in the data analysis with these levels. Additionally, of those with CP for whom classification data were collected (N_{tone} = 31, N_{type} = 39), 87% had the spastic form, a proportion relatively representative of the population with CP in which 70-80% have the spastic form (CDC, 2004).

There was greater racial diversity in the TD group versus the CP group, with 87% of the CP group being white (non-Hispanic). This was felt to be an effect of recruitment areas for the different groups. It is important to note that the groups were well matched for SES, as well as intellect (estimated by the PPVT-III), with both groups performing within average range on this measure.

Procedure

Please see measures section for details on key surveys and tasks described below.

Parents. Following informed consent, all parents were taken in to a separate waiting room and given a set of surveys to fill out regarding their child. These forms were adapted for parents in the CP group to be more applicable to their child's functional ability. All parents filled out a vision skills inventory to ensure that their child had adequate visual acuity to participate. Parents also filled out other various demographic measures. Only information from the Family Background Information (FBI) packet (see Appendix A) will be included in this analysis. This packet was filled out either during the screening by phone or at the time of the appointment. It evaluated important demographic variables such as children's functional ability through measures including GMFCS (gross motor functioning/independence), MACS (dexterity), and ExPRS (communication) (see appendix A for these separate measures). It also included questions regarding a child's age, grade, medical history, special education history, SES, and race, as well as parents' race and marital status.

Children. Children were tested, on average, for less than one hour. Following informed assent, all children were administered the main IT task (standard and adapted), the Ss task (see Figure 1A for sample; see Appendix A for complete task), the Cd task (see Figure 1B for sample; see Appendix A for complete task), and the PPVT-III (see Appendix A for sample page). Administration of these tests was pseudo randomized to ensure a counterbalanced administration.

Participant compensation. At the conclusion of the study, all children were given a stipend of $50. Primary caregivers in the CP group were also given a book entitled Cerebral palsy: A complete guide for caregiving (Miller & Bachrach, 2006).

Measures

Abbreviated Wechsler Intelligence Scale for Children—4th Edition (WISC-IV).

Symbol Search Task. The Ss task (see Figure 1A for sample; see Appendix A for complete task) is one of two core subtests of the WISC-IV (Wechsler, 2003) that is used to calculate a child's composite PS score. Children are shown two symbols and they must decide if either of these symbols appear in the group of symbols to the right. Once they make the decision, they mark a "yes" or "no" box. Scores are calculated by subtracting the number of inaccurate trials from the number of accurate of trials completed in a 120s time period. This processing speed task requires a simple gross cancellation response.

Coding Task. The Coding task (see Figure 1B for sample; see Appendix A for complete task), is one of two core subtests of the WISC- IV (Wechsler, 2003) that is used to calculate a child's composite PS score. Children are given a key presenting a set of numbers, in numerical order, matched with corresponding symbols for each number. Below this key, they are presented with a non-ordinal string of numbers without their associated symbols, and are required to reproduce the appropriate symbols below each given number in a 120s time period. Scores are calculated as the number of correct trials completed. This processing speed task requires a complex symbolic graphomotor response.

Peabody Picture Vocabulary Test-III (PPVT-III). The PPVT-III (Dunn & Dunn, 1997; see Appendix A for sample page) assesses an individual's receptive vocabulary through word-picture identification; this measure is highly correlated with verbal intellect and was used as an estimate of intellectual reasoning. Participants are given a set of four pictures and a single word. Their task is to indicate which picture the word best describes.

Statistical Analysis and Strategy

Descriptive and exploratory analyses were carried out to ensure normality of data, identify potential outliers and ensure that assumptions were met for planned analyses. Correlation analyses were carried out for variables intended for inclusion in the final analyses to test for potential colinearity. A linear regression analysis was carried out to identify significant predictors of the difference in performance between the Cd and Ss measures of processing speed (Cd (scaled score) – Ss (scaled score)). Due to insufficient numbers of participants within the dyskinetic and ataxic groups in the current sample, the distinction of subtype was not evaluated.

Results

There was no significant difference between groups (CP and TD) in estimate of intellect (PPVT-III) or SES. Not surprisingly, there was a significant difference ($p < .0001$) between the groups for gestation, with the CP group having a shorter gestation time and a wider variance. Additionally, estimate of intellect (PPVT-III standard score), Cd (scaled score), Ss (scaled score), and PS difference score were all found to be normally distributed. As expected, due to the high correlation between shorter gestation time and CP, as well as the naturally restricted range for viable gestation (no less than approximately 23 to a ceiling of approximately 40 weeks), gestation showed a negatively skewed distribution. Dexterity was positively skewed, with most participants falling into the level I category (see Figure 2; note lower score is better dexterity).

A regression analysis was carried out to test the dependence of the difference between Ss and Cd on a variety of variables hypothesized to predict PS, including group participation (TD vs. CP), intellect (estimated by PPVT-III), and dexterity (grossly estimated by MACS). Initially, gestation was a planned predictor variable to be examined, though bivariate correlations revealed

a significant correlation with CP diagnosis; this is not surprising given shortened gestation is a specific risk factor for CP (see Table 3 for a complete correlation matrix for predictor variables). Although dexterity was significantly correlated with diagnosis as well, this variable was retained in the regression analyses given dexterity was a key component of the hypothesis of the study.

The first model tested the dependence of the difference between Ss and Cd (calculated as Ss – Cd) on group participation (CP vs. TD), intellect (estimated by PPVT-III), and dexterity (measured by the MACS). To test the regression assumptions a histogram, a P-P plot of regression standardized residuals, and a scatterplot were all completed and found to be normally distributed with a linear relationship. The multiple linear regression was run using the enter method. The first model was found to explain a significant proportion of the variance in PS difference scores, Adjusted $R^2 = .19$, $F(3,135) = 11.59$, $p < .0001$. Beta coefficients are reported in Table 4.

Because the contribution of dexterity (MACS) was found not to be significant, a second model (model 2) was run without dexterity (MACS), including only group (CP vs. TD) and intellect (estimated by PPVT-III). Group was dummy coded to create an indicator variable in order to find the unique variance accounted for by diagnosis of CP when accounting for intellect. The second model was found to explain a significant proportion of the variance in PS difference scores, Adjusted $R^2 = .19$, $F(2, 136) = 17.42$, $p < .0001$. Beta coefficients are reported in Table 5.

Because of concern that there may be an interaction between the diagnosis of CP and level of measured intellect in explaining the difference between Ss and Cd, an interaction term was created by multiplying group by PPVT-III score and entered into the regression. The regression showed that this interaction was not significant in predicting the difference ($\beta = -.264$, $t_{(137)} = -.539$, $p = .591$) thus the second model was retained with group and intellect each

contributing significant and unique variance in explaining the difference between Ss and Cd (see Figure 3 for a graphic of the interaction term).

Discussion

The findings of the present study demonstrate that Cd and Ss tasks do not evaluate children with CP in the same way they evaluate TD children. Specifically, a diagnosis of CP is consistent with significantly lower performance on the Cd measure relative to performance on Ss measure in comparison to TD peers. Surprisingly, this discrepancy in performance is *not* significantly predicted by our dexterity measure (MACS). Further, this effect is observed independent of intellect (estimated by PPVT-III).

Other potential predicting factor(s)

In neuropsychological evaluations, the Ss and Cd tasks are administered under the assumption that both measure the same underlying construct, PS. Thus, the finding that these measures behave differently in the CP group raises important concerns about the appropriateness of these subtests as measures of overall PS in this population, as well as across other non-TD populations. Furthermore, while intellect predicts a greater discrepancy between performance on Cd and Ss, this is observed independent of group participation, suggesting there is something unique about group participation, above and beyond any intellectual explanation, that predicts the disparity in PS scores. While the results of the present study make this point clear, what is unclear is why. What specifically about the CP population is causing these tests to behave differently than they do in the TD population? What inherent quality does the CP population have that impedes the evaluation of the intended underlying construct (PS) in these tasks?

In the present study, it was predicted a priori that perhaps dexterity would cause this discrepancy in the CP group. However, as shown by the results, this difference was not

predicted by MACS (dexterity) ratings. This was unexpected, as motor dysfunction is the defining feature of CP, thus it is a sentinel differentiation of children with CP from their TD peers. It is possible that the absence of a finding is an artifact of the measure used. The MACS is a gross categorical evaluation of dexterity as opposed to a direct and more finely measured behavioral measure of dexterity, such as a grooved pegboard test (see Figure 4) which delineates performance at the second level. In addition to the categorical nature of the MACS, the skewed nature of the sample (see Figure 2) may have reduced the variability needed for assumptions to be held in the regression analyses. While it is anticipated that a more sensitive dexterity measure may predict a portion of the differential performance on these measures, if dexterity was a sufficiently strong predictor, its effects would have been robust enough to be seen using MACS. Thus, there are likely other factors (e.g. cognitive and/or behavioral) that explain this difference.

A potential factor could be related to the design of the tasks and the resulting strategies utilized. For instance, on the surface, the Cd task appears to have subtle different memory demands; in the Cd task the same nine symbols are repeated throughout the entire task such that learning can occur with each subsequent trial, leading to more efficient performance. In contrast, the Ss task requires participants to deal with a new set of symbols in each trial, and retention from prior trials is not a factor in efficiency. Thus, in the Cd task, it would be reasonable for a person with a relatively good working memory (WM) to keep the associated symbols and numbers in their WM (rather than referencing the key before reproducing each symbol). It is possible that those with CP may have some problem with their WM that leads them to not utilize this strategy when performing the Cd task, potentially leading to a decreased number of trials completed in the allotted time, or a decreased Cd score.

The same logic can be used when thinking through the unexpected finding that intellect (estimated by PPVT-III) is a significant predictor for differential performance on the Cd and Ss tasks, independent from group. Specifically, it appears that those with higher intellect perform better on the Ss task relative to their performance on the Cd task, and those with lower intellect perform better on the Cd task relative to their performance on the Ss task. A potential reason for this could also be related to the design of the tasks, making the Ss task relatively easier for high-intellect individuals to perform and the Cd tasks relatively easier for individuals with low-intellect. For instance, in the Cd task one must make associations between the symbols and their letters in order to be successful. However, the symbols and associated letters are presented on the same page as the string of numbers to be decoded and the same nine symbols are repeated throughout the entire task. In contrast, the Ss task requires participants to deal with a new set of symbols each trial, to evaluate the detailed difference between symbols, and to make a concrete decision (Yes or No) was either symbol present in set. There may be something about the design of and strategies employed when performing the Ss task that makes it easier for those with higher intellect to perform (relative to their performance on the Cd task) and more difficult for those with lower intellect to perform (relative to their performance on the Cd task). Similarly, there may be something about the design of the Cd task that causes the opposite effect.

Implications for practice

In addition to raising concerns about the specific features of CP that are related to this differential behavior of PS tasks, the finding also raises important broader concerns that perhaps this issue occurs in other populations or with other measures which are intended to measure similar constructs. There may be other neuropsychological measures that perform differently and need to be interpreted differently in different populations. If this is the case, then there is a

chance we are not getting the most accurate estimation or measurement of the cognition and behavior of children when we evaluate them using standard measures, particularly those measures that are potentially inaccessible due to motor, speech, or sensory demands; this is especially of concern for those with disabilities. This should serve to caution professionals carrying out formal evaluations of cognition to be cognizant of the potential biases in scores of these tasks in evaluating a child's abilities, and to take all of the child's functional abilities into account when evaluating their cognition. It is particularly important for school psychologists to recognize the complexity and limitations of these measures, as they are utilized to perform evaluations used to determine a child's special education needs and services. Most importantly, the findings of the present study point to a need to think critically of ways to adapt tasks, including neuropsychological, as well as school-related, to make them more accessible to populations like children with CP.

Limitations

Two large limitations in the present study included a lack of diversity in the dexterity of the TD group, as well as the dexterity measure itself. It is possible that a different dexterity measure or a more diverse TD population may have captured the effect of dexterity as a significant predictor for the differential performance on Ss versus Cd in children with CP. However, it is important to recognize that if dexterity was the only predictor of this difference, it would have been somewhat captured by the MACS measure, regardless of its sensitivity. Thus, another limitation to the present study is the narrow range of potential predicting factors, including other key measures of cognition, such as a simple span test (i.e. digit span).

Future Directions

While the present study importantly demonstrates that the Cd and Ss tasks behave differently in children with CP compared to their TD peers, and thus should be interpreted with caution when estimating cognitive PS, the answer to *why* is still not clear. Future studies should look at measures in the CP population which utilize timed or motor response strategies of varying degree to see their potential prediction of this difference in PS scores. It is possible that even those individuals who are able to functionally complete these tasks, may have functional deficits that are different from those intended to be measured by the target task.

Future research should also evaluate other cognitive constructs in this population, including WM, to see if a deficit of another neuropsychological ability is impeding their performance. It is important to note, however, that one needs to be careful when selecting the measures of these other abilities to ensure that motor, speech, and sensory demands do not obviously bias these scores. For example, a suitable WM task may be a digit span task.

Future studies should also look at performance patterns of these PS measures in other non-TD clinical populations. Although these measures were originally normed in largely TD populations, varying clinical populations may show similar differential performance. Accessibility difficulties and inadvertent cognitive demands may change the construct of these measures for those with CP, as well as other complex clinical populations.

While it is important to continue to work to understand how neuropsychological measures evaluate different constructs in different populations, and particularly how they should be interpreted in these populations, it is equally important to think about solutions to make these tasks more accessible to children. We must ensure that these tasks are evaluating the intended underlying construct rather than, for instance, a WM, motor, speech, or sensory difficulty. It is

important to look at adaptations and alternatives for neuropsychological measures to make certain that we capture the most accurate understanding of a child's neuropsychological functioning. For appropriate interpretations of neuropsychological assessments are vital to determining and carrying out the appropriate accommodations and interventions necessary to create the optimal school and home-environment for children.

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Table 1

Inclusion/Exclusion Criteria

***Inclusion criteria for <u>all</u> participants**:*
▪ Ages 8-16 ▪ Informed consent and/or assent within IRB guidelines.
***Exclusion criteria for <u>all</u> participants**:*
▪ Inconsistent dichotomous response despite trials with different modalities; ▪ Hearing impairment that precludes participation in tasks with verbal instructions; ▪ Visual impairments that preclude participation from judging a 10x10cm figure on a computer screen ▪ Any medical or psychiatric condition that precludes child's participation (e.g., insufficiently controlled seizure disorder, severe behavioral disorder); ▪ Unstable or frequently changing doses of medications that may affect cognitive function such as anticonvulsant medications, sedatives, and neurostimulant medications etc.; ▪ History of an acquired brain injury; i.e., TBI, stroke, encephalitis, or secondary to status epilepticus (for children with CP, this refers to events subsequent to those potentially associated with etiology of the condition); ▪ Medical or psychiatric condition that precludes parent or guardian's participation.
Specific inclusion criteria for children diagnosed with CP:
▪ Previous documented medical diagnosis of CP; ▪ Ability to communicate a dichotomous response as measured by a raw score of 12 or better on the Dichotomous Choice Screen (Appendix); ▪ Oral communicator; ▪ Level I, II, or III on the Gross Motor Functional Classification Scale (GMFCS).

Table 2a

Demographic Variables

		TD (n = 96)	CP (n = 43)
PPVT-III **(est. of intellect)**		107.7 (17.4)	102.7 (16.2)
SES		3.5 (1.3)	3.7 (1.1)
Gestation		38.0 (3.2)	32.8 (5.9)*
		% (n)	% (n)
Males		49 (47)	63 (27)
African American		28 (27)	5 (2)
Hispanic American		2 (2)	2 (1)
White (non-Hispanic)		53 (51)	86 (37)
Other		16.7 (16)	7 (3)
GMFCS **(gross motor)**	I	97 (93)	72 (31)
	II	2 (2)††	12 (5)
	III	0	16 (7)
	VI	1 (1)††	0
MACS **(dexterity)**	I	100 (96)	23 (10)
	II	0	67 (29)
	III	0	9 (4)
ExPRS **(communication)**	I	98 (94)	79 (34)
	II	2 (2)	19 (8)
	III	0	2 (1)

* $p < .0001$

† Three parents from the TD group responded with levels inconsistent with their child's functional level. Research coordinator attempted to contact parents for clarification, but was unable to reach them.

Note: Data were missing for SES ($N_{TD} = 93$) and gestation ($N_{TD} = 88$, $N_{CP} = 41$).

Table 2b

CP Classification (tone and type)

CP classification	% (n)
Tone (n = 31)	
spasticity	87 (27)
dystonia	6.5 (2)
ataxia	6.5 (2)
Type (n = 39)	
hemiplegia	43.6 (17)
diplegia	48.7 (19)
other	7.7 (3)

Note: Data were missing for tone (N = 31) and for type (N = 39)

Table 3

Intercorrelations between variables for the regression analysis

Variables	1	2	3	4
1. Group	--	-.502*	.791*	-.136
2. Gestation	--	--	-.351*	-.127
3. MACS (dexterity)	--	--	--	-.114
4. PPVT-III (est. of intellect)	--	--	--	--

* $p < 0.0001$

Table 4

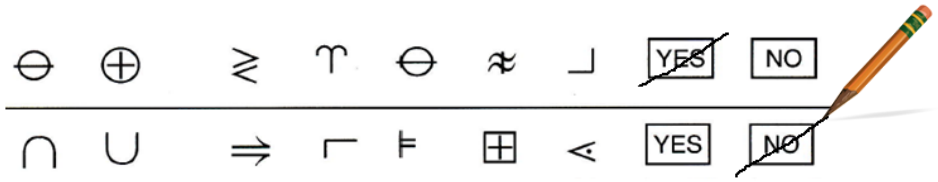
Summary of multiple linear regression for variables predicting difference in Processing Speed measures (Ss scaled score - Cd score). Model 1.

Variable	B	SE B	β	significance
Group	1.901	.729	.328	$p = .010$
MACS (dexterity)	-.258	.668	-.048	$p = .700$
PPVT-III Std. Score (est. of intellect)	.061	.012	.388	$p > .0001$

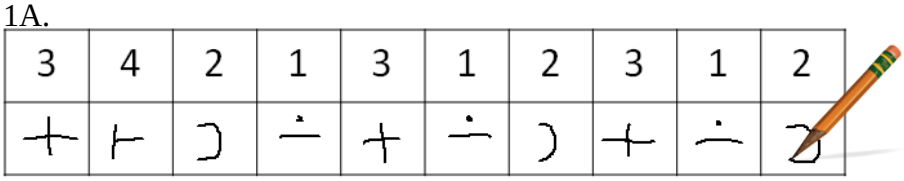
Table 5

Summary of multiple linear regression for variables predicting difference in Processing Speed measures (Ss scaled score-Cd scaled score). Model 2.

Variable	B	SE B	β	significance
Group	1.679	.447	.290	$p < .0001$
PPVT-III Std. Score (est. of intellect)	.061	.012	.388	$p < .0001$



1A.



1B.

Figure 1. Examples of Processing Speed tests.

1A. Example of Symbol Search Task (simple gross cancellation task)

1B. Example of Coding Task (complex symbolic graphomotor task)

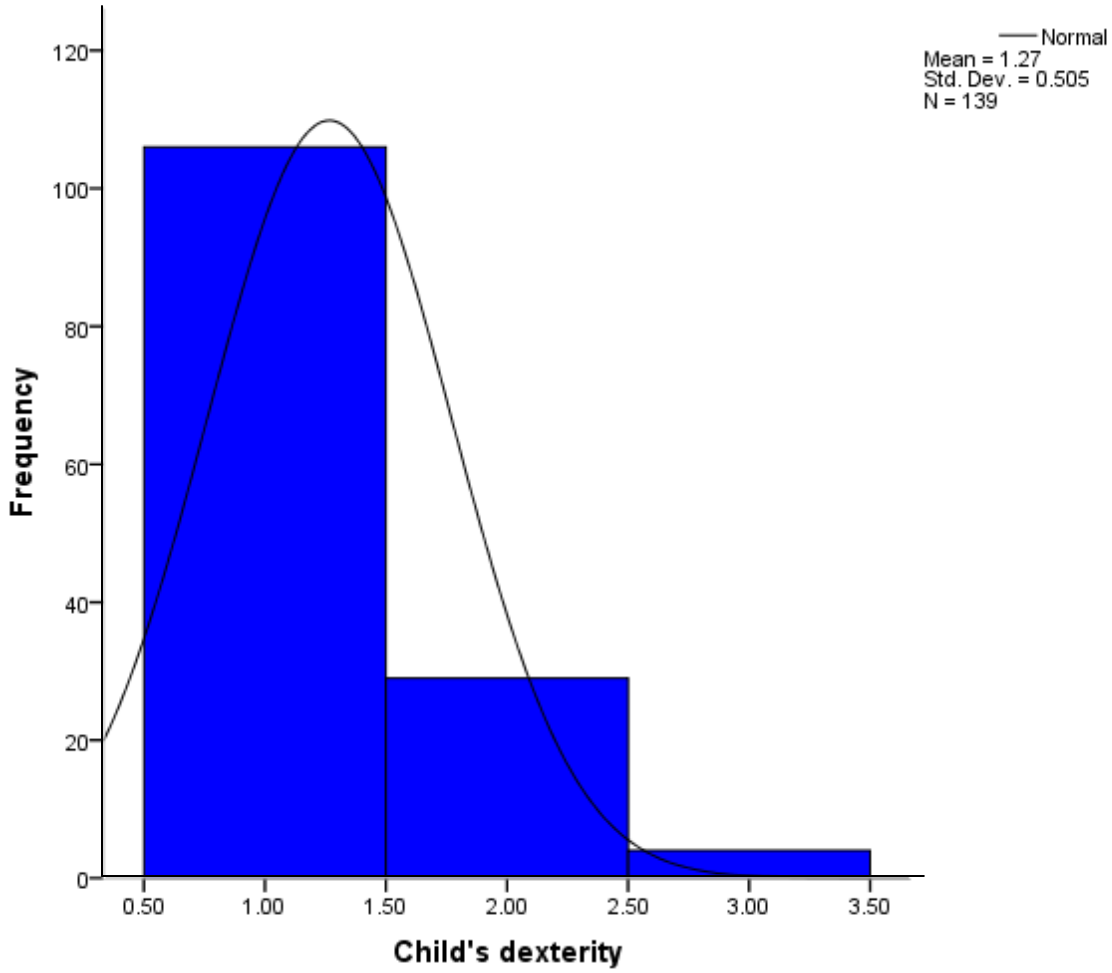


Figure 2. Distribution of dexterity (measured by MACS) for all participants. Lower MACS scores indicate better dexterity.

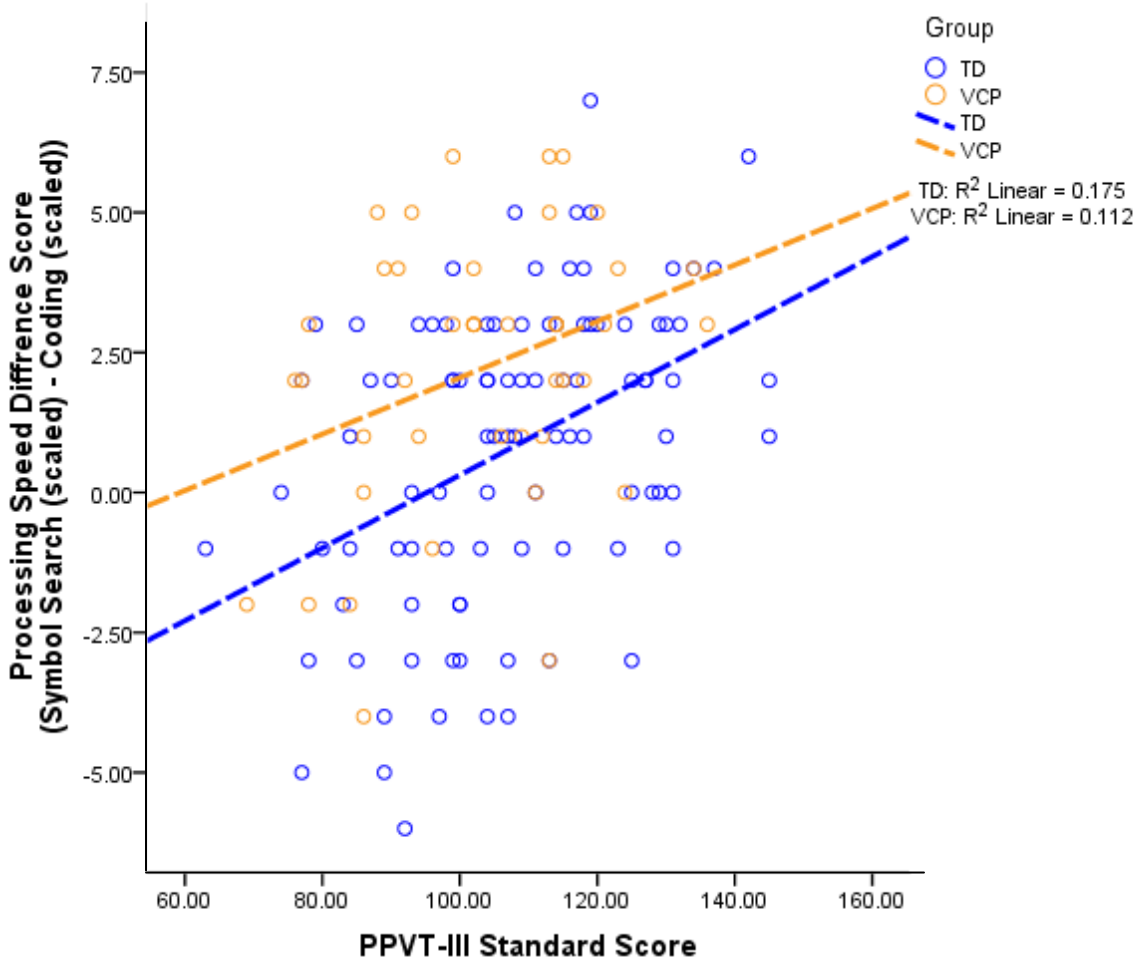


Figure 3. Intellect (estimated by PPVT-III) versus PS difference score (Ss-Cd) for TD versus CP groups. This figure demonstrates that there is no interaction effect for group by PPVT-III when predicting PS difference score.

Figure 4. Sample photo of the grooved pegboard task ("Evaluation: Grooved Pegboard", n.d.).

This task is a potential alternative or supplementary measure of dexterity to MACS.

Appendices

Appendix A:

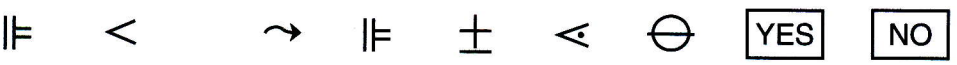
Participant Measures

Symbol Search B

Ages 8–16

SAMPLE ITEMS

PRACTICE ITEMS



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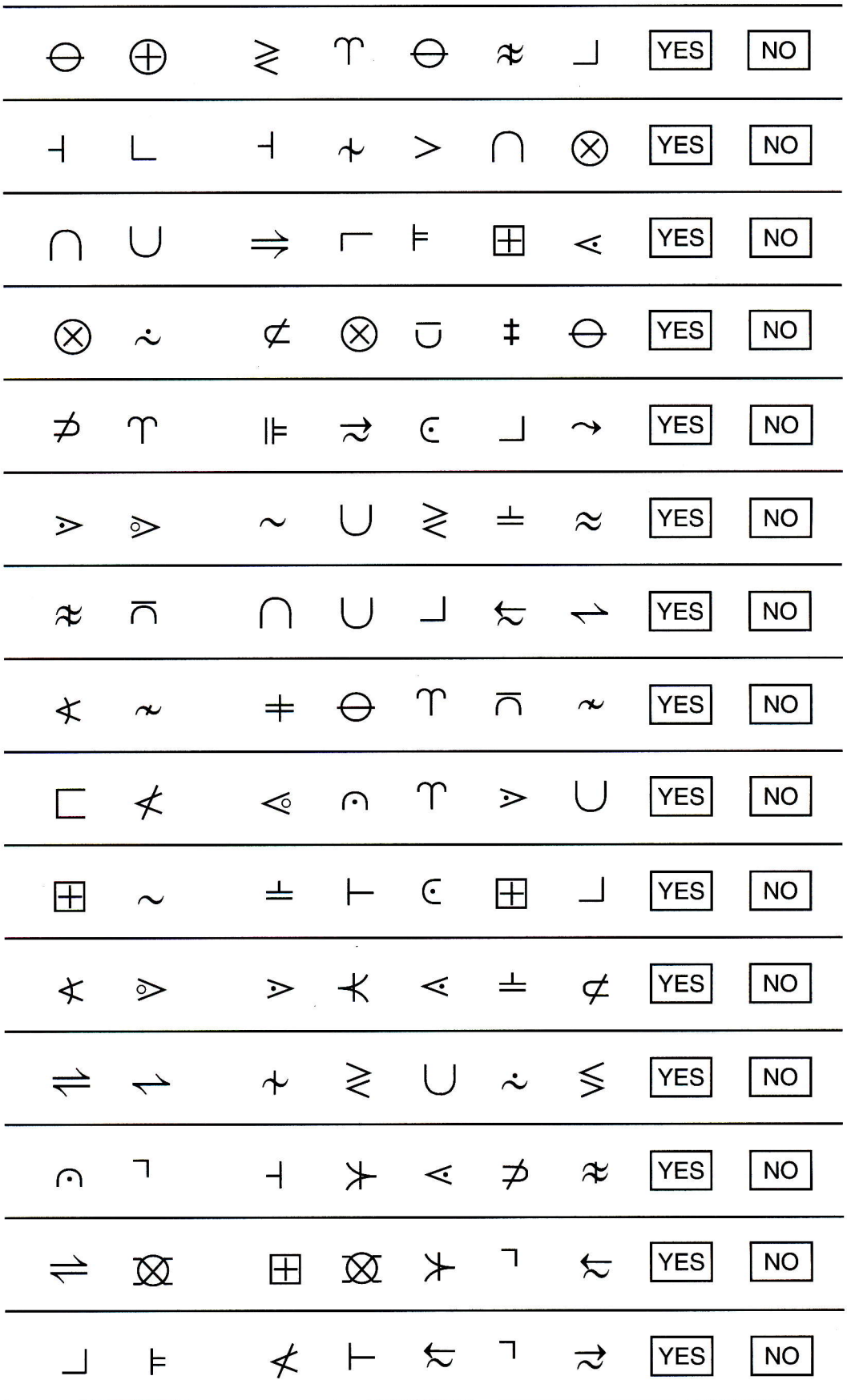
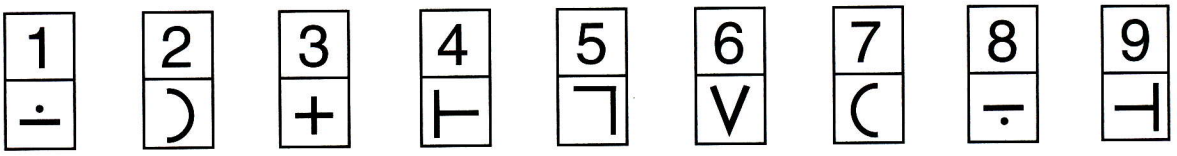


C I

Coding B

Ages 8–16



SAMPLE ITEMS

2	1	4	6	3	5	2	1	3	4	2	1	3	1	2	3	1	4	2	6	3

1	2	5	1	3	1	5	4	2	7	4	6	9	2	5	8	4	7	6	1	8

7	5	4	8	6	9	4	3	1	8	2	9	7	6	2	5	8	7	3	6	4

5	9	4	1	6	8	9	3	7	5	1	4	9	1	5	8	7	6	9	7	8

2	4	8	3	5	6	7	1	9	4	3	6	2	7	9	3	5	6	7	4	5

2	7	8	1	3	9	2	6	8	4	1	3	2	6	4	9	3	8	5	1	8

Family Background Information

Person filling out this form (circle one): child's mother child's father guardian

Child's gender (circle one): male female

Child's age: _____ Date of birth: _____ Current grade: _____

Child's primary medical diagnoses, if any (for example, "cerebral palsy"):

_____

If your child is diagnosed with cerebral palsy, please check:

_____ hemiplegia _____ diplegia

Primary tone/movement difficulty
_____ spasticity
_____ dystonia
_____ choreoathetosis
_____ ataxia

Secondary tone/movement difficulty
_____ spasticity
_____ dystonia
_____ choreoathetosis
_____ ataxia

Siblings

Male/Female	Age	Does sibling live in the home? (Y/N)	Does sibling have a disability? (Y/N)	Biological or Step Sibling?

Child's relationship to you (place check in front of one):

_____ your biological child by current marriage
_____ your biological child by another marriage
_____ your spouse's biological child (your stepchild)
_____ your adopted child
_____ your biological child but you are not married
_____ other (please describe): _____

Child's race/ethnicity (place check in front of best description):

_____ African American
_____ Hispanic American
_____ White (non-Hispanic)
_____ Other _____

Your Age _____

Your marital status (place check in front of best description):

_____ never married
_____ married
_____ divorced/separated
_____ widowed
_____ unmarried, live with partner

Your employment (title/position):_____

Your education (please check highest level obtained):
_____ some high school
_____ high school diploma
_____ some college
_____ technical or associates degree
_____ bachelors degree
_____ graduate school degree

Your spouse's age (if applicable): _____

Employment (title/position):_____

Education (please check highest level obtained):
_____ some high school
_____ high school diploma
_____ some college
_____ technical or associates degree
_____ bachelors degree
_____ graduate school degree

Annual Household Income (total income from all sources last year)
_____ less than $22,000
_____ $22,000 – $35,000
_____ $35,000 - $50,000
_____ $50,000 – $75,000
_____ $75,000 – $100,000
_____ more than $100,000

Child's Independence Mark the item that best describes your child's typical abilities:

___ Walks without restrictions; limitations in more advanced gross motor skills.
___ Walks without assistive devices; limitations walking outdoors and in the community.
___ Walks with assistive mobility devices; limitations walking outdoors and in the community.
___ Self-mobility with limitations; child is transported or use power mobility outdoors and in the community.
___ Self-mobility is severely limited even with the use of assistive technology.

Child's Dexterity Mark the item that best describes your child's typical abilities:

___ Handles objects easily and successfully.
___ Handles most objects but with somewhat reduced quality and/or speed of achievement.
___ Handles objects with difficulty; needs help to prepare and/or modify activities.
___ Handles a limited selection of easily managed objects in adapted situations.
___ Does not handle objects and has severely limited ability to perform even simple actions.

Child's Communication Mark the item that best describes your child's typical abilities:

___ Speaks in a generally age-appropriate way; minor limitations, if any.
___ Speaks with some difficulty; speech may be slow or somewhat difficult to understand by a new listener.
___ Speaks with significant difficulty; speech is slow or quite difficult to understand by a new listener.
___ Communicates independently with limitations; individual uses adapted techniques such as signing, or an augmentative communication device.
___ Communication is severely limited even with the use of augmentative technology.

Child's Understanding Mark the item that best describes your child's typical abilities:

___ Understands sign, verbal, and/or written language in a generally age-appropriate way.
___ Understands and responds (with action, gesture, or words) to questions about people or things not present at the time (e.g., "Where do you want to go?").
___ Understands and responds (with action or vocal reply) to simple commands (e.g., "Show me your nose.") or preferences (e.g., "Do you want some milk?").
___ Understands and responds (by orienting or shifting activity) to the sound/sign of own name and the word/gesture "no."
___ Understands and responds (through facial or postural changes) to attention and affection.

Medical History (Please circle YES or NO; <u>if YES, briefly describe treatment</u>):

Number of weeks pregnant at birth _____

YES NO Premature baby?

Weight at Birth:___lbs ___oz

YES NO Low Birth Weight?

YES NO Intraventicular hemorrhage (IVH) at birth?

If YES grade of IVH (if known) _____

YES NO Other birth complications:_____

YES NO Seizure _____

YES NO Scoliosis _____

YES NO Hydrocephalus _____

YES NO Spasticity _____

YES NO Pain _____

YES NO Visual Impairments _____

YES NO Hearing Impairments _____

YES NO Speech Impairments _____

Does your child receive Special Education services? YES NO

What is your child's Special Education Classification please circle:

POHI PI OHI CI SLI SXI LD Other

_____

What type of Special Education services does your child receive (for example, speech, PT, OT, resource room, etc.), please list:

_____

Has your child ever received speech therapy: yes no

If yes:
How long have they received speech therapy: _____ group individual both

Where does your child receive speech therapy: school private both

What are some of your child's speech goals? Please list: _____

_____

_____

_____

_____

_____

Prior Surgeries (also note if surgeries are planned):

Intervention	Date

Current Medications - Please list all of the medication(s) your child is currently taking along with the dosage, reason for the medication, and side effects:

Name of Medication	**Dosage**	**Reason for Medication**	**Side Effects?** (e.g. fatigue or alertness)

For the following 6 questions please rate each item according to how much you agree or disagree with each statement. If you strongly disagree with the statement, you would circle 1. If you strongly agree with the statement, you would circle 5. Circle 2, 3, or 4 for ratings in between.

	Strongly Disagree	Disagree	Neutral	Agree	Strongly Agree
To what extent do **you** feel that your child:					
Has an attention deficit?	1	2	3	4	5
Has hyperactivity?	1	2	3	4	5
Has impulsivity?	1	2	3	4	5
To what extent do you feel **others** perceive that your child:					
Has an attention deficit?	1	2	3	4	5
Has hyperactivity?	1	2	3	4	5
Has impulsivity?	1	2	3	4	5

Is there any other information you can share with us that might help us to test your child's learning skills?

☐ No

☐ Yes – If yes, please explain.

GMFCS: Gross Motor Function Classification Scale (Palisano et. al., 1997)

___ Walks without restrictions; limitations in more advanced gross motor skills.

___ Walks without assistive devices; limitations walking outdoors and in the community.

___ Walks with assistive mobility devices; limitations walking outdoors and in the community.

___ Self-mobility with limitations; child is transported or use power mobility outdoors and in the community.

___ Self-mobility is severely limited even with the use of assistive technology.

MACS: Manual Ability Classification System (Eliasson A, Krumlinde SL, Rosblad B, et al., 2006)

___Handles objects easily and successfully.

___ Handles most objects but with somewhat reduced quality and/or speed of achievement.

___Handles objects with difficulty; needs help to prepare and/or modify activities.

___Handles a limited selection of easily managed objects in adapted situations.

___Does not handle objects and has severely limited ability to perform even simple actions.

ExPRS: Expressive Production Rating Scale (Van Tubbergen, Albright et al., 2005)

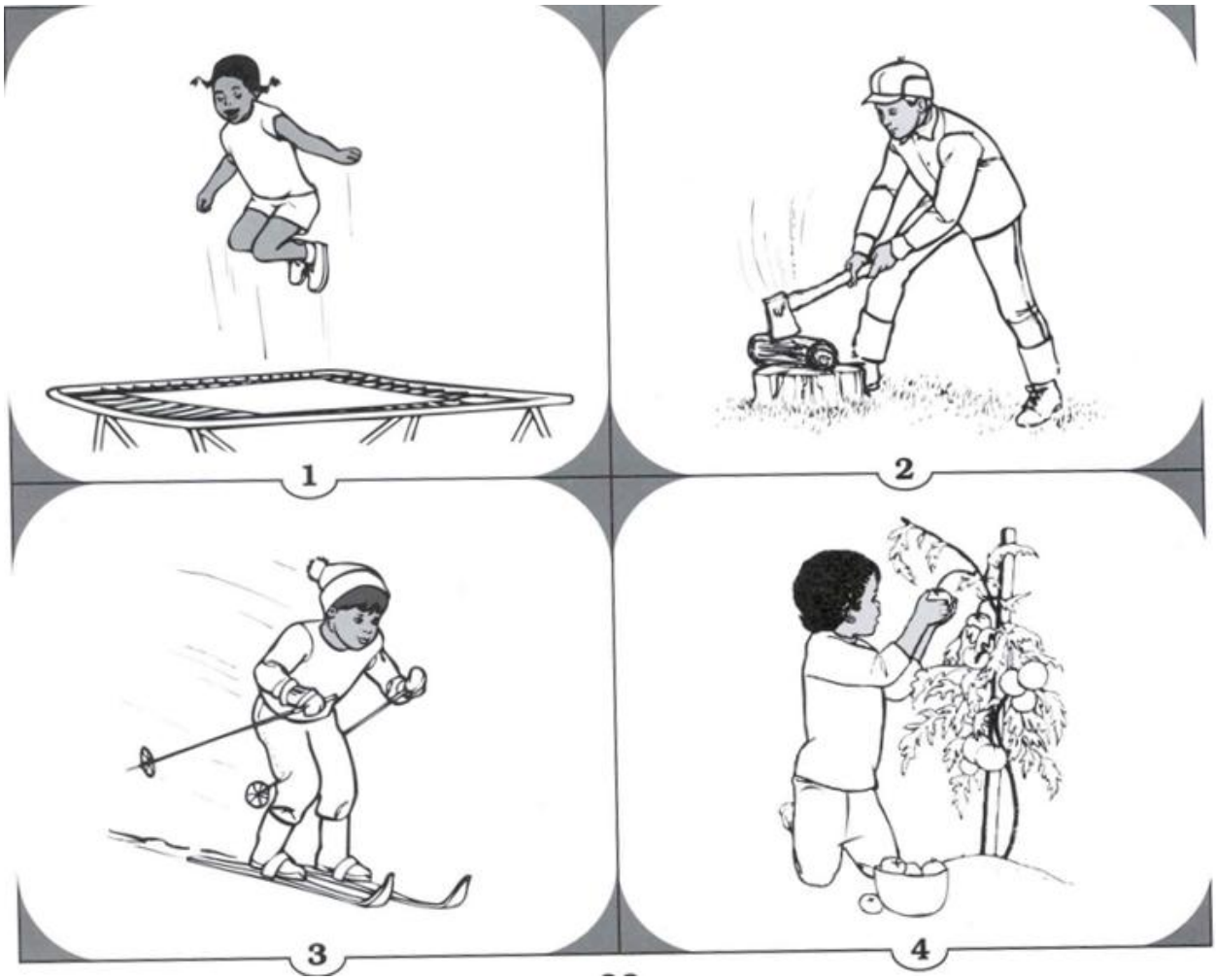
___ Speaks in a generally age-appropriate way; minor limitations, if any.

___ Speaks with some difficulty; speech may be slow or somewhat difficult to understand by a new listener.

___ Speaks with significant difficulty; speech is slow or quite difficult to understand by a new listener.

___ Communicates independently with limitations; individual uses adapted techniques such as signing, or an augmentative communication device.

___ Communication is severely limited even with the use of augmentative technology.



Participants are given a set of four pictures and a single word.
Their task is to indicate which picture the word best describes.

Appendix B:

Recruitment and Screening Forms

Research Opportunity:
Testing Your Child's Thinking Speed

The University of Michigan Health System and Mary Free Bed Rehabilitation Hospital are conducting research on new ways of testing children's thinking speed. Children who take part will be able to try computerized tests of thinking speed. To take part in this study, children must:

- Have a medical diagnosis of ***Cerebral Palsy***
- Be 8-16 years of age
- Have their parent (or legal guardian) provide written, informed approval to participate
- Have no changes in medication dosage within the past 3 month
- No history of an acquired brain injury which occurred later in childhood

Participants can expect to spend two to three hours in the study, and will be paid a $50.00 honorarium for their time and effort.

To schedule an appointment please call
(734) 936-6604 or (734) 763-6189

For more information, please contact:
Donna Omichinski
325 E. Eisenhower, Third Floor
Ann Arbor, MI 48109
ACAL-Research@umich.edu
(***NOTE***: please indicate "Processing Speed" in the subject line of your e-mail)

Visit the Adapted Cognitive Assessment Lab website for more information at:
http://sitemaker.umich.edu/acal/home



IRB: HUM00014311

Research Opportunity:
Testing Your Child's Thinking Speed

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- Be 8-16 years of age
- Have their parent (or legal guardian) provide written, informed approval to participate,
- Have no medical or psychiatric condition that affects the tests, including changing doses of medication or a history of brain injury.

Participants can expect to spend two to three hours in the study, and will be paid a $50.00 honorarium for their time and effort.

To schedule an appointment please call
(734) 936-6604 or (734) 763-6189

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Donna Omichinski
325 E. Eisenhower, Third Floor
Ann Arbor, MI 48108
ANAC-Project@med.umich.edu
(***NOTE***: please indicate "Processing Speed" in the subject line of your e-mail)

Visit the Adapted Cognitive Assessment Lab website for more information at:
http://www.med.umich.edu/pmr/acal/index.htm



IRBMED # HUM00003052

University of Michigan
Health System
Physical Medicine
and Rehabilitation

Thinking Speed Study

ACAL - Adapted Cognitive Assessment Lab

What is Thinking Speed?

Thinking speed or information processing speed is the amount of time it takes your brain to process simple information. Traditional tests of thinking speed and vocabulary can only be given to children with typical speech and movement, so those tests are not accessible to many children who have disabilities, including children with Cerebral Palsy, because answers must be given by speaking, pointing, or writing the answer. But just because you move slowly, doesn't mean that you think slowly!

This study is designed to separate physical capabilities from measurement of thinking capabilities. We do this with tests of Visual Inspection Time. Visual Inspection time is measured by the amount of time a person needs to look at something before they can correctly make a simple judgment about what they just saw.

Who can participate in the Thinking Speed Study?

Children, ages 8 through 16 with or without cerebral palsy and their parent or guardian who must be present for the child's test appointment. Children must have at least a consistent ability to indicate choice (yes and no), an ability to hear spoken instructions, be able to see large pictures on a computer screen, possess a stable medical status, and no history of brain injury apart from the cause of the cerebral palsy.

What will my child do during the research project?

The child will participate in tests of vocabulary and thinking speed in which he/she is given verbal instructions, shown pictures, and makes a choice about the correct response through the use of assistive technology (i.e., pressure switch). We ask a small number of children to take some of the tests a second time for reliability purposes. Children, who are able, will also be asked to speak and point to their responses during their participation. The activities are similar to the types of activities done in regular school or psychological test settings.

While the child is testing, the parent/guardian will complete surveys that ask questions about their child's quality of life, family history, and the child's history.

How long does the testing take?

Testing will take up to 2 hours. Additionally, a random group of children will also be asked to return in 2-3 weeks from the date of the original test date for reliability purposes. You will be informed upfront if you have been selected to be invited for a reliability testing visit.

What will I learn from my child's participation in this research?

Because this is research, there is no guarantee that this will benefit any particular child who participates in this study.

Who should I contact?

To schedule an appointment or to answer questions, call (734) 936-6604 or (734) 763-6189. You can also e-mail this study team at ACAL-Research@umich.edu .

This study is funded by the National Institutes of Health and the U.S. Department of Education and has been approved by the University of Michigan's Institutional Review Board and committee on human subjects' research (IRB # HUM00014311).

University of Michigan
Inspection **T**ime

Intake Form

Inclusion criteria – for **ALL** children

☐ Yes ☐ No	Is the child 8 -16 years of age and currently in school?
☐ Yes ☐ No	Does the child have a hearing or vision impairment? If yes, is it treated successfully? ☐ Yes ☐ No Hearing ☐ yes ☐ no Vision ☐ yes ☐ no
☐ Yes ☐ No	Does the child have any type of clinically diagnosed medical or psychological condition (e.g. ADHD, seizures, depression)? If yes, is it successfully treated/managed? ☐ No for TD kids
☐ Yes ☐ No	Is the child currently taking any medications? If yes, has there been a change of medications within the last 3 months? List Meds: ☐ No for TD kids
☐ Yes ☐ No	Do you, as the parent, have a medical or psychological condition that would interfere with your participation in this study? (completing background forms or signing consent)
☐ Yes ☐ No	Would you, as the parent, require an interpreter or someone to assist you with reading?
☐ Yes ☐ No	Has your child ever had a neuropsychological evaluation? If yes, when was the most recent evaluation?
	Can your child distinguish between left and right? ☐ yes ☐ no
	Can your child distinguish between short and long? ☐ yes ☐ no

Inclusion Criteria – for children **WITH CP**

☐ Yes ☐ No	Is there a documented diagnosis of CP? Who made the dx?
☐ Yes ☐ No	Is your child's speech understood by an unfamiliar listener? If **NO**, does the child have an effective, alternate communication system? ☐ Yes ☐ No If **YES**, what type of device?
☐ Yes ☐ No	Does you child have experience making choices using pictures? ☐ Yes ☐ No Give example: Can your child consistently answer questions? ☐ Yes ☐ No For example: Can you child chose a preferred food or activity? Give example: Can your child consistently answer factual questions? For example: If you show 4 pictures of animals, can they show you the cat? ☐ Yes ☐ No If you show 3 pieces of clothing can they identify the shirt? ☐ Yes ☐ No Give example:

- **Does your child receive special education services?** ☐**YES** ☐**NO**

  If yes, under what educational service label: POHI PI OHI CI SLI SXI LD Other

  What type of services does your child receive (ie **–** speech, occupational therapy, physical therapy, resource room services, self-contained classroom, etc.)**:**

- **Does the parent understand that they must be available for the Informed Consent prior to their child's participation in research? YES** ☐ **NO** ☐

- **Does the parent agree to complete questionnaires and that requires ~1 hour of their time?**
  YES ☐ **NO** ☐

IRBMED # HUM000014311
3/17/2011

University of Michigan
Inspection **T**ime

Intake Form

Participant Profile

☐ **NVCP:** Does child have a clear Yes/No ability? Specify: _____

☐ **VCP:** Is family willing to come back in 2-3 weeks as part of the study? ☐ Yes ☐ No

☐ **TD**

NVCP & VCP use of AT device?

☐ Yes ☐ No

Type of AT _____

Is the child familiar with computer scanning – ie high lighted box around the object of choice? ☐ Yes ☐ No

Appears to Meet Criteria

☐ Not Sure
↳ Need follow-up _____

☐ No
↳ Reason for exclusion _____

☐ Yes
⇩

Appointment

☐ Date: _____ Time: _____

☐ Informed family of no guarantee into study based on screening.

☐ Cancelled & Reschedule date: _____

☐ No Show/No Call: _____

☐ Entered into Master List: YES NO

Notes:

IRBMED # HUM000014311
3/17/2011

Dichotomous Choice Screen

Van Tubbergen, Warschausky, & Ayyangar, 2005

Name _____ Date _____

Orientation

Yes No **The child will gaze at Card 1 for 3 seconds** (present card 2' away)

Yes No **The child will shift gaze between Card 1 and Card 2** (present cards 2' away, 18" apart. Shake Card 1 (right hand) for 5 seconds, then shake Card 2 for 5 seconds, then shake Card 1 again for 5 seconds. Do not verbally direct child.)

Yes No **The child will shift gaze between Card 2 and Card 1** (present cards 2' away, 18" apart. Shake Card 2 (right hand) for 5 seconds, then shake Card 1 for 5 seconds, then shake Card 2 again for 5 seconds. Do not verbally direct child.)

Discrimination

Yes No **The child will shift gaze on command** (present Cards 2 (right hand) and 3 (left hand), 18" apart and 2' away. Say, *"child's name, look at the dog."* Switch cards so Card 2 is in left hand, Card 3 in right hand. Represent cards and say, *"Now find the dog again."*)

Yes No **The child will shift gaze on command** (present Cards 1 (right hand) and 4 (left hand), 18" apart and 2' away. Say, *"child's name, look at the house."* Switch cards so Card 1 is in left hand, Card 4 in right hand. Represent cards and say, *"Now find the house again."*)

Matching

Yes No The **child will shift gaze to identify a match** (present Card 2, say "*Look at this.*" While holding Card 2, display Card 5 underneath and say "*Find the same.*")

Yes No The **child will shift gaze to identify a match** (present Card 4, say "*Look at this.*" While holding Card 2, display Card 6 underneath and say "*Find the same.*")

Yes No The **child will shift gaze to identify a match** (present Card 2, say "*Look at this.*" While holding Card 2, display Card 7 underneath and say "*Find the same.*")

Yes No The **child will shift gaze to identify a match** (present Card 4, say "*Look at this.*" While holding Card 2, display Card 8 underneath and say "*Find the same.*")

Using Yes/No

Yes No **The child will demonstrate a yes response on command** ("Show me how you say "yes.") Response _____

_____

Yes No **The child will demonstrate a no response on command** ("Show me how you say "no.") Response _____

_____

Answering specific questions using yes/no: (Present all cards 2' away, in the line of child's vision)

0/1	Say:	Child's response:	
_____	**"Is this a turtle?"** (Present Card 3)	Yes	No
_____	**"Does he have wings?"** (Present Card 3)	Yes	No
_____	**"Is this an airplane?"** (Present Card 4)	Yes	No
_____	**"Is this a house?"** (Present Card 4)	Yes	No

Card 1 = black and white checkerboard Card 2 = flower Card 3 = dog Card 4 = house Card 5 = flower (R) and checkerboard (L)
Card 6 = house (R) and dog (L) Card 7 = checkerboard (R) and flower (L) Card 8 = dog (R) and house (L)

Appendix C:

Consent and Assent

UNIVERSITY OF MICHIGAN
CONSENT TO BE PART OF A RESEARCH STUDY

INFORMATION ABOUT THIS FORM

You may be eligible to take part in a research study. This form gives you important information about the study. It describes the purpose of the study, and the risks and possible benefits of participating in the study.

Please take time to review this information carefully. After you have finished, you should talk to the researchers about the study and ask them any questions you have. You may also wish to talk to others (for example, your friends, family, or other doctors) about your participation in this study. If you decide to take part in the study, you will be asked to sign this form. *Before you sign this form, be sure you understand what the study is about, including the risks and possible benefits to you.*

1. GENERAL INFORMATION ABOUT THIS STUDY AND THE RESEARCHERS

1.1 Study title:

EVALUATION AND APPLICATION OF AN ADAPTED MEASURE OF INSPECTION TIME OF CHILDREN WITH CEREBRAL PALSY (THINKING SPEED STUDY)

1.2 Company or agency sponsoring the study:

U.S. Department of Education; National Institutes of Health

1.3 Names, degrees, and affiliations of the researchers conducting the study:

Seth Warschausky, Ph.D., Department of Physical Medicine and Rehabilitation, University of Michigan; Marie Van Tubbergen, Ph.D., Department of Physical Medicine and Rehabilitation, University of Michigan; Jacqueline Kaufman, Ph.D., Department of Physical Medicine and Rehabilitation, University of Michigan; Rita Ayyangar, M.D., Department of Physical Medicine and Rehabilitation, University of Michigan; Edward Hurvitz, M.D., Department of Physical Medicine and Rehabilitation, University of Michigan

2. PURPOSE OF THIS STUDY

2.1 Study purpose:

Traditional tests of vocabulary and thinking speed can only be given to children with typical speech and movement capabilities. This study examines new ways of testing the thinking speed of children with cerebral palsy who have speech and movement difficulties and compares their performance on these adapted tests to that of typically developing children.

3. INFORMATION ABOUT STUDY PARTICIPANTS (SUBJECTS)

Taking part in this study is completely **voluntary**. You do not have to participate if you don't want to. You may also leave the study at any time. If you leave the study before it is finished, there will be no penalty to you, and you will not lose any benefits to which you are otherwise entitled.

3.1 Who can take part in this study?

Children, ages eight through sixteen with or without cerebral palsy and their parent or guardian who must be present for the child's test appointment. Children must have at least a consistent ability to indicate choice, ability to hear spoken instructions, stable medical status and no history of brain injury apart from the cause of the cerebral palsy.

3.2 How many people (subjects) are expected to take part in this study?

120 children are expected to participate, 60 at the University of Michigan and 60 at Mary Free Bed Hospital. 120 parents/guardians will complete questionnaires about their children.

4. INFORMATION ABOUT STUDY PARTICIPATION

4.1 What will happen to me in this study?

The child will participate in tests of vocabulary and thinking speed in which he/she is given verbal instructions, shown pictures, and makes a choice about the correct response. The parent completes a brief interview about the family background, the child's capabilities and history. In order to confirm that research results are reliable, we need a small number of children to take some of the tests a second time. We will offer this additional opportunity to some randomly selected participants. The data gathered from all parts of participation will be stored in an electronic database.

We may like to videotape the child during the study activities, and to use the images for a variety of educational purposes, such as presentation at scientific meetings. If you do not want your child to be videotaped during the study, your child will not be videotaped, and you are still eligible to participate in the research project.

I agree to have my child photographed/videographed for this study.
Please initial preference: _____ YES _____ NO

I would like to receive information about ACAL research finds and future research opportunities.
Please initial preference: _____ YES _____NO

I would like to receive information about the ACAL Education Liaison service.
Please initial preference: _____ YES _____ NO

I would like to have my child's name and address added to the ACAL registry.
Please initial preference: _____ YES _____ NO

4.2 How much of my time will be needed to take part in this study?

The child's participation will last 2-3 hours for the session. Some children will be invited to participate in two sessions, with the second session 2-4 weeks after the first session. It will take the parent/guardian approximately one hour to complete the questionnaires about the child.

4.3 When will my participation in the study be over?

The child's participation will last 2-3 hours for the session. Some children will be invited to participate in two sessions, with the second session 2-4 weeks after the first session. It will take the parent/guardian approximately one hour to complete the questionnaires about the child.

5. INFORMATION ABOUT RISKS AND BENEFITS

5.1 What risks will I face by taking part in the study? What will the researchers do to protect me against these risks?

The known or expected risks are minimal but include the possibility of fatigue or agitation. The parent and staff will be present to monitor the child's reactions, take breaks or stop the assessment as needed. The study will require approximately three hours of the child's time. Participation is voluntary, and we will try to schedule appointments that are convenient for you. All data gathered from child and parent(s) participation will be labeled only with a unique research number, not with a name or other identifying information. Names and other identifying information will be linked to research numbers on a master list, which will kept in a secure location and destroyed at the completion of the study.

As with any research study, there may be additional risks that are unknown or unexpected.

5.2 What happens if I get hurt, become sick, or have other problems as a result of this research?

The researchers have taken steps to minimize the risks of this study. Even so, you may still have problems or side effects, even when the researchers are careful to avoid them. Please tell the researchers listed in Section 10 about any injuries, side effects, or other problems that you have during this study. You should also tell your regular doctors**.**

5.3 If I take part in this study, can I also participate in other studies?

Being in more than one research study at the same time, or even at different times, may increase the risks to you. It may also affect the results of the studies. You should not take part in more than one study without approval from the researchers involved in each study.

5.4 How could I benefit if I take part in this study? How could others benefit?

You may not receive any personal benefits from being in this study. You and your child may find it beneficial to have exposure and practice with new technologies for making choices. Your participation in this study is anticipated to help psychologists and school provide more accurate test results for children with movement and speaking impairments

5.5 Will the researchers tell me if they learn of new information that could change my willingness to stay in this study?

Yes, the researchers will tell you if they learn of important new information that may change your willingness to stay in this study. If new information is provided to you after you have joined the study, it is possible that you may be asked to sign a new consent form that includes the new information.

6. OTHER OPTIONS

6.1 If I decide not to take part in this study, what other options do I have?

The study is completely voluntary and you or your child may decide that you do not want to participate or stop participating at any time.

7. ENDING THE STUDY

7.1 If I want to stop participating in the study, what should I do?

You are free to leave the study at any time. If you leave the study before it is finished, there will be no penalty to you. You will not lose any benefits to which you may otherwise be entitled. If you choose to tell the researchers why you are leaving the study, your reasons for leaving may be kept as part of the study record. If you decide to leave the study before it is finished, please tell one of the persons listed in Section 10 “Contact Information” (below).

7.2 Could there be any harm to me if I decide to leave the study before it is finished?

No, there will be no harm if you decide to leave the study.

7.3 Could the researchers take me out of the study even if I want to continue to participate?

Yes. There are many reasons why the researchers may need to end your participation in the study. Some examples are:

- ✓ The researcher believes that it is not in the child or parent's best interest to stay in the study.
- ✓ The child or parent becomes ineligible to participate.
- ✓ The condition of the child or parent/guardian changes and requires treatment that is not allowed while taking part in the study.
- ✓ The child or parent/guardian does not follow instructions from the researchers.
- ✓ The study is suspended or canceled.

8. FINANCIAL INFORMATION

8.1 Who will pay for the costs of the study? Will I or my health plan be billed for any costs of the study?

The study will pay for research-related items or services that are provided only because you are in the study. If you are not sure what these are, see Section 4.1 above or ask the researchers for a list. If you get a bill you think is wrong, call the researchers' number listed in section 10.1.

You or your health plan will pay for all the things you would have paid for even if you were not in the study, like:

- Health care given during the study as part of your regular care
- Items or services needed to give you study drugs or devices
- Monitoring for side effects or other problems
- Treatment of complications
- Deductibles or co-pays for these items or services.

If you do not have a health plan, or if you think your health plan may not cover these costs during the study, please talk to the researchers listed in Section 10 below or call your health plan's **medical reviewer.**

By signing this form, you do not give up your right to seek payment if you are harmed as a result of being in this study.

8.2 Will I be paid or given anything for taking part in this study?

Yes, a stipend for $50.00 dollars will be sent to the home in the parent/guardian's name intended as payment to the child for participation. If the child participates in a second, shorter session, there will be an additional $25.00 paid.

8.3 Who could profit or financially benefit from the study results?

No one is expected to profit or financially benefit from the study results.

9. CONFIDENTIALITY OF SUBJECT RECORDS AND AUTHORIZATION TO RELEASE YOUR PROTECTED HEALTH INFORMATION

The information below describes how your privacy and the confidentiality of your research records will be protected in this study.

9.1 How will the researchers protect my privacy?

Research records will be kept in a separate research file that does not include names, registration numbers, or other information that is likely to allow someone other than the researchers to link the information to you.

9.2 What information about me could be seen by the researchers or by other people? Why? Who might see it?

Signing this form gives the researchers your permission to obtain, use, and share information about you for this study, and is required in order for you to take part in the study. Information about you may be obtained from any hospital, doctor, and other health care provider involved in your care, including:

- Hospital/doctor's office records, including test results (X-rays, blood tests, urine tests, etc.)
- Mental health care records (except psychotherapy notes not kept with your medical records)
- Alcohol/substance abuse treatment records
- Your AIDS/HIV status
- All records relating to your condition, the treatment you have received, and your response to the treatment
- Billing information

There are many reasons why information about you may be used or seen by the researchers or others during or after this study. Examples include:

- The researchers may need the information to make sure you can take part in the study.
- The researchers may need the information to check your test results or look for side effects.

- University, Food and Drug Administration (FDA), and/or other government officials may need the information to make sure that the study is done in a safe and proper manner.
- Study sponsors or funders, or safety monitors or committees, may need the information to:
    - Make sure the study is done safely and properly
    - Learn more about side effects
    - Analyze the results of the study

Insurance companies or other organizations may need the information in order to pay your medical bills or other costs of your participation in the study.

- The researchers may need to use the information to create a databank of information about your condition or its treatment.
- Information about your study participation may be included in your regular UMHS medical record.
- If you receive any payments for taking part in this study, the University of Michigan accounting department may need your name, address, social security number, payment amount, and related information for tax reporting purposes.
- Federal or State law may require the study team to give information to government agencies. For example, to prevent harm to you or others, or for public health reasons.

The results of this study could be published in an article, but would not include any information that would let others know who you are.

9.3 What happens to information about me after the study is over or if I cancel my permission?

As a rule, the researchers will not continue to use or disclose information about you, but will keep it secure until it is destroyed. Sometimes, it may be necessary for information about you to continue to be used or disclosed, even after you have canceled your permission or the study is over. Examples of reasons for this include:

- To avoid losing study results that have already included your information
- To provide limited information for research, education, or other activities (This information would not include your name, social security number, or anything else that could let others know who you are.)
- To help University and government officials make sure that the study was conducted properly

As long as your information is kept within the University of Michigan Health System, it is protected by the Health System's privacy policies. For more information about these policies, ask for a copy of the University of Michigan Notice of Privacy Practices. This information is also available on the web at http://www.med.umich.edu/hipaa/npp.htm. Note that once your information has been shared with others as described under Question 9.2, it may no longer be protected by the privacy regulations of the federal Health Insurance Portability and Accountability Act of 1996 (HIPAA).

9.4 When does my permission expire?

Your permission expires at the end of the study, unless you cancel it sooner. You may cancel your permission at any time by writing to the researchers listed in Section 10 "Contact Information" (below).

10. CONTACT INFORMATION

10.1 Who can I contact about this study?

Please contact the researchers listed below to:

- Obtain more information about the study
- Ask a question about the study procedures or treatments
- Talk about study-related costs to you or your health plan
- Report an illness, injury, or other problem (you may also need to tell your regular doctors)
- Leave the study before it is finished
- Express a concern about the study

Principal Investigator: Seth Warschausky, Ph.D.
Mailing Address: Department of Physical Medicine and Rehabilitation; 325 E. Eisenhower Pkwy, Suite 100, Ann Arbor, MI 48108
Telephone: (734) 936-7051

Co-Investigators: Jacqueline Kaufman, Ph.D.; Marie Van Tubbergen, Ph.D
Mailing Address: Department of Physical Medicine and Rehabilitation; 325 E. Eisenhower Pkwy, Suite 100, Ann Arbor, MI 48108
Telephone: (734) 936-7051

You may also express a concern about a study by contacting the Institutional Review Board listed below, or by calling the University of Michigan Compliance Help Line at 1-888-296-2481.

University of Michigan Medical School Institutional Review Board (IRBMED)
Argus I
517 W. William
Ann Arbor, MI 48103-4943
Telephone: 734-763-4768
Fax: 734-615-1622
e-mail: irbmed@umich.edu

If you are concerned about a possible violation of your privacy, contact the University of Michigan Health System Privacy Officer at 1-888-296-2481.

When you call or write about a concern, please provide as much information as possible, including the name of the researcher, the IRBMED number (at the top of this form), and details about the problem. This will help University officials to look into your concern. When reporting a concern, you do not have to give your name unless you want to.

11. RECORD OF INFORMATION PROVIDED

11.1 What documents will be given to me?

Your signature in the next section means that you have received copies of all of the following documents:

- ☐ This "Consent to be Part of a Research Study" document. (*Note: In addition to the copy you receive, copies of this document will be stored in a separate confidential research file and may be entered into your regular University of Michigan medical record.)*
- ☐ Other (specify):_____

12. SIGNATURES

Research Subject:

I understand the information printed on this form. I have discussed this study, its risks and potential benefits, and my other choices with _____. My questions so far have been answered. I understand that if I have more questions or concerns about the study or my participation as a research subject, I may contact one of the people listed in Section 10 (above). I understand that I will receive a copy of this form at the time I sign it and later upon request. I understand that if my ability to consent for myself changes, either I or my legal representative may be asked to re-consent prior to my continued participation in this study.

Signature of Subject: _____ Date: _____

Name (Print legal name): _____

Patient ID: _____ Date of Birth: _____

Legal Representative (if applicable):

Signature of Person Legally Authorized to Give Consent _____ Date: _____

Name (Print legal name): _____ Phone: _____

Address: _____

Check Relationship to Subject:

☐Parent ☐Spouse ☐Child ☐Sibling ☐Legal Guardian ☐Other: _____

If this consent is for a child who is a ward of the state (for example a foster child), please tell the study team immediately. The researchers may need to contact the IRBMED.

Reason subject is unable to sign for self: _____

_____

Principal Investigator (or Designee):

I have given this research subject (or his/her legally authorized representative, if applicable) information about this study that I believe is accurate and complete. The subject has indicated that he or she understands the nature of the study and the risks and benefits of participating.

Name: _____ Title: _____

Signature: _____ Date of Signature: _____

Witness (optional):

I observed the above subject (or his/her legally authorized representative, if applicable) sign this consent document.

Name: _____

Signature: _____ Date of Signature: _____

Study No.:
IRB: #HUM00014311 **Consent Approved On: 10/07/2007** **Project Approval Expires On: 9/30/2010**

Child's Assent to Participate in Research Project
at the University of Michigan

I want to tell you about being in a research study.

A research study is a way to learn new things.
This study is to learn if tests on computers are the same as tests in books.
If you are in the study, you will be asked to take the tests, which are like tests you take at school.
You do not have to be in the study if you do not want to be.
Even if you start the study, you may change your mind and quit later.
You and your parents (mother/father) can ask questions about the study and your questions will be answered.
Your parents (mother/father) may stay with you all the time.

Printed name of child _____

Circle
Y or N: Have parent(s) interpret Y/N signal if unclear

Y N **Do you know that this study is to learn if computer tests are the same as book tests?**

Y **N** **Do you have to do this study?**

Y N **Do you want to do this study?**

_____ _____
Signature of parent as witness Date

_____ _____
Signature of Investigator Date