ADAPTIVE SKILLS AND SCHOOL READINESS IN CHILDREN WITH DOWN SYNDROME

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Submitted in partial fulfillment of the requirements for Departmental Honors in the Department of Kinesiology
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Fort Worth, TX

May 6 2019
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CHILDREN WITH DOWN SYNDROME

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ABSTRACT

The purpose of this study was to examine the influence of adaptive skills on school readiness in children with Down syndrome. Participants included 12 (6 male, 6 female; ages 4-6) children with Down syndrome who attend a laboratory school serving children ages 2-6 with intellectual and developmental disabilities. To assess adaptive skills, parents of the participants completed the Vineland II. The Vineland II focuses on several relevant areas including communication, daily living skills, socialization, motor skills, and maladaptive or behavior index. School readiness was objectively assessed with the International Development and Early Learning Assessment (IDELA). The IDELA measures motor development, language, problem solving, and socio-emotional skills. Expressive communication skills ($r = 0.7$, $p<0.05$) and personal daily living skills ($r = 0.68$, $p<0.05$) had the strongest relationship to overall school readiness. Together, those two variables explained 48% of the variance for school readiness. Normative scores show participants were delayed in their expressive language, receptive language, and personal daily living skills. Occupational therapists are positioned to help children with Down syndrome and their families develop treatment programs to increase meaningful engagement and school readiness. One way to address this need could be through focusing on expressive language and personal daily living skills.
ACKNOWLEDGEMENTS

Thank you to the Kinderfrogs School at TCU for their willingness to allow this project to occur on their campus with their students as participants. Thank you to Dr. Phil Esposito and the TCU Kinesiology Department for their support and guidance throughout the completion of this project.
INTRODUCTION

Down Syndrome

In the United States, 6,000 babies will be born with Down syndrome (DS) over the next year (Parker, 2010). This amounts to about 1 in every 700 babies born, making it the most common chromosomal disorder of today. 40 children are born with DS are born in Tarrant County alone every year. Due to the prevalence of DS, it is important that research be conducted to determine the best way to educate children with DS so they can live happy, healthy, and productive lives. Surprisingly, little research surrounding early intervention and preparation for school life for children with DS exists.

Children with DS experience decreased muscle tone, flattened and small facial features, and short hands with short fingers (Bull, 2011). The most common cause of DS is nondisjunction, or the failure of a pair of chromosomes to separate, causing an extra 21st chromosome (Safford, 2008). This accounts for 95% of cases and is called Trisomy 21. Mosaicism is another form of DS, where some cells have the typical 46 chromosomes where others have 47. This form is the rarest, at only 1% of cases. The final 4% of DS cases are caused by a condition called Translocation, which occurs when a copy of chromosome 21 attaches to another pair of chromosomes (National Down Syndrome Society, 2019).

DS is also the most commonly known genetic cause of intellectual disability. In children with DS, intellectual disability can range from little to severe- but 80% show moderate intellectual disability. This means that an individual with DS’s IQ will likely range from 40-70 (Hodapp et. al., 1999). This is because the brain of a child with DS is microcephalic, with a small hippocampus, prefrontal cortex, and cerebellum (Roberts et. al, 2016).

The intellectual disability these children experience causes cognitive barriers such as a shortened attention span, memory deficits, lack of executive function, delayed speech
development, and slower learning (Bull, 2011; Iacono, 2010; Pennington, 2003; Rowe, 2006). For example, language development, especially expressive language, is incredibly difficult because of slurred speech and an inability to understand grammar. Often, nonverbal communication in children with DS is much more advanced because they understand more than they can express (Ivic, 2016). Many children with DS are held back from kindergarten, sometimes for 2 or 3 years. Often this is due to a lack of school readiness when compared to typically developing children of the same age.

**Adaptive Skills**

In order for a person to be independent, he/she must possess a certain amount of adaptive skills. Adaptive skills include anything which one might need to be independent, including the ability to upkeep personal hygiene, (i.e. personal daily living skills), communicate with others by both understanding and being able to express themselves, (i.e. expressive and receptive communication), interact in social environments, (i.e. social skills), and physically complete certain tasks (i.e. motor skills).

Children with DS are significantly delayed in acquiring adaptive skills due to the developmental delays discussed previously (Van Duijn et. al., 2010). While researchers have found deficits in all adaptive skills, the weakest skill is expressive language (Dykens et. al., 2006). Dykens et. al. additionally found increased variance among older individuals with DS when compared to their younger peers, suggesting that adaptive skills plateau sometime in the middle childhood age range. This further supports the importance of early intervention and development of adaptive skills early in life, as the child’s support team must work hard to get them to a high level of adaptive functioning before that plateau.

**School Readiness**
School readiness is difficult to define, but the consensus is that school readiness includes any skill a child might need to enter the formal schooling system (Pentimonti et. al, 2016). Quantifying school readiness is a difficult task, for there is not one factor that contributes to it, but instead there are many. The constructs examined in the IDELA are some of these factors. School readiness and the general social and practical abilities that come with it are incredibly important for the future of the child. Without the necessary skills, children will not succeed in school and go on to be productive members of society.

People with Down syndrome who have better behavior and a higher level of functional activities and daily living are more likely to participate in open employment events and to eventually acquire a job (Foley et. al, 2016). These activities of daily living and behavior skills are likely to be learned in a school setting as well as in the home. Therefore, it is important that children with DS are ready to properly learn at school so that they can get the most out of their experience.

**KinderFrogs**

The KinderFrogs School at TCU is a laboratory school at Texas Christian University which serves as an early intervention preschool for children with DS and other developmental disabilities. The program started in 2000, after the Fort Worth community noticed the need for such a program as one did not exist in the area. Currently, the school serves around 35 students in three different classes: Toddler, Pre-K, and LEAP. The classes are generally split up by age, with Toddler housing 1.5-3 year-olds, Pre-K housing 3-5 year-olds, and LEAP housing 5-7 year-olds.

Daily activities in each classroom include circle-time, snack and lunch, craft activities, adapted physical education, outside playground exploration, and free-time to explore and learn in the classroom. Students are additionally pulled out of the classroom on an individual basis to go
to occupational therapy and speech therapy. The goal of the KinderFrogs staff is to an inclusive kindergarten setting following their experience at KinderFrogs.

The KinderFrogs school served as the inspiration for this research project. The principle researcher has spent ample time both volunteering in the classroom as well as shadowing the occupational therapist. This time with the students at KinderFrogs brought forward the question, “What skills do these children need to possess in order to make them the readiest for any future schooling they may engage in?”

**Purpose and Hypothesis**

The purpose of this study is to look at the different categories of adaptive skills in this population and how they correlate with school readiness scores to hopefully determine a set of skills that are most important in ensuring that this population is school ready as early as possible. The researchers hypothesize that the participants will have deficits in all of the adaptive skills categories, but that expressive language will have the largest deficit. The researchers also hypothesize that social skills and language skills will have the highest correlation to school readiness.

**METHODS**

**Participants**

Nine children diagnosed with DS (3 boys and 6 girls) ages 2 - 6 years were recruited from the Kinderfrogs school on the TCU campus. Only students from the older two classes, LEAP (ages 5-7 years) and Pre-K (ages 3-4 years), were used. Exclusion criteria included dual-diagnoses (i.e. autism). Individuals were not excluded based on the type of DS (i.e. Mosaicism, Trisomy 21, or Translocation).

**Instruments**
The Vineland Adaptive Behavior Skills, Second Edition (Vineland II; Sparrow, 2005) was developed by Sara Sparrow and colleagues in 2005 to determine developmental delays in individuals from birth to 90 years old. It is a survey of a series of questions rating adaptive skills in four different categories: communication (expressive and receptive), socialization, motor skills (fine and gross) and personal daily living skills. Each skill listed in the Vineland II is rated on a scale of 0-2 with 0 meaning the individual cannot complete the task and with 2 meaning the individual can complete the task always. The Vineland II can be filled out whether by interviewer rating or parent/caregiver rating. For the purposes of this study, the parent/caregiver rating forms were used. The survey generally takes about 35-40 minutes to complete. Scores from each domain as well as a sum score were calculated, and scores were compared using normative data included in the Vineland II.

The IDELA was used to objectively measure the school readiness of each of the participants. The IDELA was created by the Save the Children foundation in order to measure the early learning and development of children across the globe to determine school readiness. The IDELA measures motor development, language, problem solving, and socio-emotional skills (About IDELA, 2019). There are 24 tasks included in the assessment. Tools necessary to complete the IDELA assessment include blocks, picture cards, beans or similar small countable materials, and drawing materials. Tasks include an array of challenges such as drawing a human figure, counting, and some socioemotional questions such as “how do you think this girl is feeling?” when shown a picture of a crying girl. The scores from each subdomain of the assessment as well as the sum score will be calculated, and results will be compared to the
Vineland II results in order to determine trends. The assessment took approximately 30 minutes per participant.

**Procedures**

Consent forms were completed prior to the gathering of data. Forms were sent home in the folders of each of the potential participants (children in the Pre-K and LEAP classes at the KinderFrogs school). After receiving consent forms, the assessments could begin.

During the designated biweekly occupational therapy time of each participant, the principle researcher and the participants’ occupational therapist administered the IDELA assessment. Prior to the assessment, in order to engage the participant, the researcher would ask, “Can we play today?” This served as a motivator as well as verbal consent prior to the test. All efforts were made to conduct the assessment all at one time, though some students required breaks due to attention difficulties or negative behavior such as throwing assessment materials. The assessment questions were given in the same order for each participant to normalize factors such as lack of attention towards the end of the test. The assessment took approximately 30 minutes for each participant, depending upon the speed at which participants could complete each task. For some tasks which were more verbal, a waiting period of about a minute was given before moving on to the next item if the participant was declining to respond. Participants were given praise and encouragement in equal amounts throughout the test to keep motivation levels as high as possible.

After administering the IDELA, the Vineland II survey was sent home with the child and a reminder email was sent to each parent, explaining how to fill out the survey. Parents were free to fill out the survey at their leisure and were asked to return the survey within a week of its receipt. The survey typically takes about 30 minutes to fill out. The completed surveys were
collected by the KinderFrogs school secretary and then given back to the principle researcher to be scored.

RESULTS

A correlation test was conducted to determine the relationship between each adaptive skill and overall school readiness scores. Expressive communication skills \( (r = 0.7, p<0.05) \) as well as personal daily living skills \( (r = 0.68, p<0.05) \) had the strongest correlation to school readiness. Expressive communication skills and personal daily living skills accounted for 48\% of the variance for school readiness. Additionally, when comparing to normative scores, every participant scored below the norm for school readiness.

DISCUSSION

The purpose of this study was to determine which adaptive skills correlated to higher school readiness scores in children with DS as well as determine where the participants have deficits in these adaptive skills. Similar to Dykens et. al. in 2006, this study found that the participants were delayed in every adaptive skills category, validating the hypothesis in this regard. Contrary to the hypothesis, however, this study found that expressive language as well as personal daily living skills were most important for a higher school readiness score. Additionally, the researchers found that the participants were below the normative scores in all areas tested in the Vineland.

Unfortunately for this population, expressive language has been found to be the most challenging adaptive skill for children with DS. Therefore, it is important to put an emphasis on this skill in speech and occupational therapy as well as in the classroom. Ensuring that the child can communicate for him/herself will help in a traditional kindergarten because the child can
then communicate their needs and wants. If the child cannot express that they “need more snack,” then the child’s needs will never be adequately met. One way to get around this deficit is by using sign language or “baby signs,” as Özçalisğan et. al. found in 2016. By teaching “baby signs,” or simple sign language geared towards the needs of the child at that age, the researchers were able to predict an increase in expressive vocabulary a year after the introduction of the signs. The use of this sign language in replace of verbal language (which might be difficult for a child with DS) might help to increase expressive language later in life.

As for personal daily living skills, there needs to be an intersection between the goals of the occupational therapist, teacher, and parent to establish skills which lead to independence. Does the child eat by themselves all of the time, or only at school? Progress in this area will be made more quickly if it stretches across all domains of the child’s life. Additionally, this skill is important for school readiness as the child will have less individualized attention in a traditional school and will need to be able to take care of themselves more than they would in the Kinderfrogs classroom. An occupational therapist can be of additional help with tasks such as dressing, feeding, grooming, and more. With some work and patience, it is possible to improve these skills in children with DS so they can be more successful at school and away from their parents.

As far as addressing the deficits in adaptive skills overall, parents, Occupational Therapists, and all other individuals on the child’s “team” need to be aware of the inherent deficits which come with the intellectual disability. It is going to take extra work and dedication to get a child with DS to a level where they can be successful in traditional kindergarten, as the researchers have shown here with the lack of scores above the normative values. Being aware of these inherent differences in learning is important for the child’s success. This population is
capable of such incredible learning and growth as long as they have a dedicated team of patient teachers, therapists, and parents who care about their success.

**Limitations**

Improvements could have been made to this study by increasing the sample size, possibly by recruiting outside of the Kinderfrogs population. Many participants were lost during the *Vineland II* survey portion of the study. Some parents waited a long time to complete the *Vineland II*, simply did not respond to emails and never turned it in or filled it out incorrectly despite the instructions sheet included. This diminished the pool of participants even further as data from the participants which did not turn in a *Vineland II* could not be used. This additionally delayed the researchers from running statistics until many *Vineland II* surveys were returned to the parents with renewed instructions and then collected again. If the study were to be repeated, casting a wider original net of participants would be ideal so that the result pool of participants is larger.

**Future Questions**

A future study could examine these same variables in a typically developing population, comparing the school readiness needs of typically developing preschoolers with this population. This would determine if specialized attention is needed across the entirety of the age group, and if the adaptive strengths of all individuals of this age are the same. Children with DS are not the only individuals who need a little bit of extra help to get ready for kindergarten, so having a reference like this for the typically developing population could help their growth as well. Additionally, the comparison of children with DS who do not attend a specialized school like KinderFrogs to those who do needs to be examined. This would help to determine what effects this type of school have on children with DS and would potentially help to explain the importance of lab schools like KinderFrogs. If the KinderFrogs School at TCU can be shown to
be more effective in creating school-ready children, then there could be a good argument to create more schools like it.
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