MEDICAL SCIENCE MONITOR BASIC RESEARCH

HUMAN STUDY

e-ISSN 2325-4416
© Med Sci Monit Basic Res, 2018; 24: 159-167
DOI: 10.12659/MSMBR.910448

Received: 2018.04.07
Accepted: 2018.07.26
Published: 2018.10.16

Contribution of Physical and Motor Characteristics to Functional Performance in Children and Adolescents with Down Syndrome: A Preliminary Study

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Source of support: Departmental sources

Background: Down syndrome (DS) is the most frequent genetic mental disability. Individuals with DS experience a variety of physical, motor, and functional challenges throughout the lifespan. However, the inter-relatedness between these domains is relatively unexplored in children with DS. This study aimed to determine which physical and motor characteristics contribute to functional performance in children and adolescents with DS. It also investigated the relationship between physical, motor, and functional domains.

Material/Methods: We enrolled 44 children and adolescents with DS, ages 3–18 years, in this cross-sectional study. The participants were assessed for functional skills (PEDI-CAT), gross motor skills (GMFM-88), balance (PBS), fine motor skills (Nine-hole peg test), grip strength (hand-held Jamar dynamometer), and body mass index (BMI). Descriptive statistics, Pearson's correlation, and stepwise linear regression were employed for statistical analysis.

Results: Fine motor skills and grip strength were found to be significant predictors of functional performance. All measures, except BMI, were significantly correlated with each other. The participants scored below standard values in all 4 domains of PEDI-CAT, with the social/cognitive skills being most impaired, while mobility proficiency was found to be participants' strongest asset.

Conclusions: This study demonstrated fine motor skills and grip strength to be predictors of functional performance in children and adolescents with DS. It also showed a high level of inter-relatedness between the variables of physical, motor, and functional domains in this population.

MeSH Keywords: **Activities of Daily Living • Down Syndrome • Hand Strength • Motor Skills**

Full-text PDF: https://www.basic.medscimonit.com/abstract/index/idArt/910448

Background

Down syndrome (DS), first described by Dr. John Langdon Down in 1866, is the most common genetic mental disability [1]. Although DS is most commonly associated with intellectual disability, equally important deficiencies are experienced within the physical, motor, and functional domains. Besides the presence of common health problems [2], the prevalence of obesity was also reported to be significantly higher in youth with DS in comparison to their typically developing peers [3].

It is reasonable to suggest that body composition and muscle strength might serve as control parameters for gross motor, balance, fine motor, and functional performance in school-aged children with and without DS. The muscular strength in persons with DS is affected by various clinical symptoms, including orthopedic, neurological, and cognitive impairments [4]. Children with DS have impaired grip and pinch strength, which are thought to improve with training [5]. Although very limited in number, all studies on grip strength in youngsters with DS report lower force in relation to their peers without intellectual disability [5,6].

The development of motor behavior in children with DS shows another profile of the typically developing population. There are descriptions of specific body posture and movements [7,8], delayed or poorly developed motor development [6,9], and increase in developmental delay with the increase in complexity of the motor skill [10,11]. Despite studies reporting fine motor skills to be less impaired than gross motor skills [12], it is argued that poor fine motor skills may limit the performance of complex functional skills of daily living [13].

The functional skills of individuals with DS have been also reported to be impaired. The activities of self-care involving fine motor skills were described to be most delayed, whereas mobility performance appears to be a stronger aspect of functioning [13]. Motor ability was found to be a much stronger predictor of functional performance in children with DS than mental performance ability [14].

While the literature strongly suggests that youngsters with DS experience multi-domain deficits, their inter-relatedness remains unclear. This study aimed to show which physical and motor characteristics contribute to functional performance in children and adolescents with DS. It also investigated the relationship between physical, motor, and functional domains.

Material and Methods

Participants and data acquisition

The study was carried out at the premises of Down Syndrome Kosova (DSK) Organization (a national organization representing the rights of individuals with DS in Kosovo), at the centers in the cities of Prishtina, Prizren, Ferizaj, and Mitrovica, during the period September 2016 to May 2017. Parents/guardians of 44 children with DS, aged 3–18 years, agreed to their children's participation and signed the informed consent. The children did not present with major health conditions that would be counter to mild physical exertion (e.g., cardiac problems or uncontrolled seizures), and conditions that would greatly affect overall physical performance, such as neurological conditions (e.g., hemiparesis). The permission for development of this study was granted by the Oversight Board for Professional Ethics of the Ministry of Health in the Republic of Kosovo, protocol no. 05-2295.

The assessments were conducted in 2 sessions scheduled within the same week. At the first session, all participants (n=44) were assessed for GMFM-88, PBS, and BMI. At the second session, some parents/guardians and their children did not show up, or children failed to follow the instruction or to cooperate; therefore, at the second session, from the original sample of 44 participants, 34 were additionally assessed for PEDI-CAT, 27 for both PEDI-CAT and 9-HPT, and finally 26 for all 3 of the remaining variables (PEDI-CAT, 9-HPT, and grip strength). The number of subjects assessed for each variable during the first and second sessions are shown as a flow chart in Figure 1.

Physical features

BMI (body mass index) is a measure for determination of overweight and obesity. It was calculated by dividing weight in kilograms by height in meters squared. Overweight is defined as a BMI at or above the 85th percentile and below the 95th percentile, while obesity is defined as BMI in the 95th percentile for children and teens of the same age and sex [15,16].

The Jamar, a calibrated hydraulic dynamometer, was utilized for evaluation of maximum hand grip strength. The dynamometer was used in position "2", and the recommendations of the American Society of Hand Therapists for a standardized position were followed [17,18]. The act of squeezing was demonstrated and explained to each child with 1 or more efforts. Then, the children were asked to squeeze the Jamar as hard as possible with one hand. The duration of the contraction was 3–5 s. Verbal encouragement was given during the test. Three repetitions were performed, alternating the assessed limb, with a 1-min interval between each attempt. The best measure achieved between the 3 collected ones was taken into

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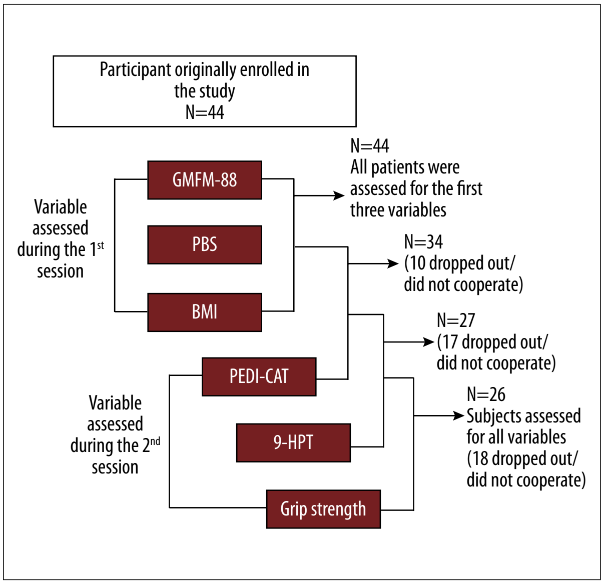

Figure 1. A flow chart showing the number of patients assessed for each of the variables. At the first session, all participants (n=44) were assessed for GMFM-88, PBS, and BMI. The remaining 3 variables were assessed during the second session and were from the original sample of 44 participants; 34 were additionally assessed for PEDI-CAT, 27 for PEDI-CAT, and 9-HPT, and finally 26 for all 3, PEDI-CAT, 9-HPT, and grip strength. GMFM-88 – Gross Motor Function Measurement-88; PBS – Pediatric Balance Scale; PEDI-CAT – Pediatric Evaluation of Disability Inventory-Computer Adaptive Test; 9-HPT – Nine-Hole Peg Test; BMI – Body Mass Index.

consideration. The dominant side was tested first. Calibration of the Jamar dynamometer was checked before, after, and periodically during the study.

Motor skills

GMFM-88 was used to obtain an estimation of participants' gross motor function. GMFM-88 is an 88-item measure originally developed for assessment of children with cerebral palsy, but it has also been validated for use with children with DS [19]. The GMFM-88 is appropriate for children with DS whose motor skills are at or below those of a 5-year-old child without any motor disability. The maximum possible score is 100. Administering the GMFM-88 took approximately 45–60 min per child. As instructed, the testing was done without shoes. All other assessment guidelines and criteria described in the test manual were fully followed [20].

Body balance was assessed using the PBS [21,22] among children who were able to stand and walk independently. All 14 items of PBS were assessed on the criterion-based 0–4 scale. A child who successfully completed all the tasks could gain a maximum of 56 points. The nearer to maximum the score is, the better the functional balance in the context of everyday life.

The commercially available Nine-hole peg test (9-HPT) was used to measure manual dexterity. The 9-HPT is considered a quick and easy to administer tool for screening fine motor problems in children. It is a timed test in which 9 pegs are inserted and removed from 9 holes in the pegboard with each hand. At the present time, to the best of our knowledge, no studies have used the 9-HPT to document dexterity variability in children with DS.

Participants were tested individually in a quiet location. Children were tested at a desk and chair of appropriate height with their feet supported on the floor. The pegboard was centered in front of the subject with the container side on the same side as the hand being tested. Hand dominance was determined simply by asking the child's parent/caregiver. The dominant hand was tested first. Subjects completed 1 practice trial followed by the actual timed test for each hand. The instructions used were the same as those used by Mathiowetz et al. [23]. For the non-dominant hand, the pegboard was turned so that the container was on the same side as the non-dominant hand.

Functional performance

Functional abilities were evaluated using PEDI-CAT, a computer adaptive test (CAT) which is the revision of the Pediatric Evaluation of Disability Inventory (PEDI) originally published in 1992 [24]. The PEDI-CAT covers ability measurement in 3 functional domains: Daily Activities, Mobility, and Social/Cognitive. The last domain, Responsibility, measures the amount of responsibility undertaken by a caregiver and/or a child in dealing with more complex tasks of everyday life. In this study we used the Speedy ("Precision") version of CAT, which administers 10–15 items per domain. PEDI-CAT can be used with all clinical diagnoses and in various community settings. It is designed for use with children and youth (birth through 20 years of age) with a variety of physical and/or behavioral conditions [25]. The purpose of using PEDI-CAT in this study was evaluation of current functional abilities and identification of functional delay in children and adolescents with DS. It was administered by a physical therapist, who verbally asked questions to the parent/caregiver of the child being assessed, and entered the answers into the program. The PEDI-CAT software uses Item Response Theory (IRT) statistical models for estimation of a child's abilities. The 3 Functional Skill domains of Daily Activities, Mobility, and Social/Cognitive are rated on a 4-point Difficulty Scale ranging from 'Unable' to 'Easy'. The responses for Responsibility domain range from 'Adult/caregiver has full responsibility' to 'Child takes full responsibility without any direction, supervision, or guidance from an adult/caregiver', which are scored on a 5-point Responsibility Scale. The results were

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presented as normative scores (provided as T-scores) that interpret functional skills of a child with DS in comparison to children with typical development of the same age. For each year of age, the mean is 50 with a standard deviation of 10, where typically the scores between 30 and 70 (i.e., mean ±2 standard deviations) are considered within the expected range for age. However, scaled scores, which are helpful in estimating child's current functioning and improvement over time without comparing them to normative data, were also utilized when considered appropriate (as described in the following paragraph).

Statistical analysis

Data were analyzed with SPSS software (SPSS, v. 23.0 for WINDOWS; SPSS Inc., Chicago, IL, USA). Descriptive statistics are provided for all examined variables. Contribution of other (independent) variables to each of the 4 (dependent) variables corresponding to 4 sections of PEDI-CAT was explained using stepwise linear regression analyses (significance level at $p<0.05$). Covariates for the regression models were selected on the basis of theoretical considerations and correlation analyses. All stepwise regression models included the covariates of GMFM-88, 9-HPT, grip strength, age, and BMI. PBS was excluded due to its strong correlation with the GMFM-88 ($r=0.856$, $p<.001$). The 3 PEDI-CAT sections that were momentarily not being tested as a criterion (dependent) variable were excluded due to multicollinearity. The models using right versus left 9-HPT performance and grip strength were selected because it explained more of the variance in functional performance. PEDI-CAT scaled scores were used in correlation and regression analyses to provide more accurate results because only PEDI-CAT computed T-scores and scaled scores, while all other tested variables provided only scaled scores.

Results

Patients' demographic and clinical data are presented in Table 1. All variables were showed in scaled scores except for the 4 sections of PEDI-CAT, which were presented in T-scores. In a typically developing population, the mean for each age group is 50, with a SD of 10, where scores between 30 and 70 (i.e., mean +2 SD) are considered within the expected range, it can be noted that none of the participants reached the mean score of 50 in PEDI-CAT sections.

All examined variables were found to be significantly correlated among each other, except for BMI, which was not correlated to any of the variables (Table 2). As expected, Daily activities section was meaningfully correlated with the other 3 sections of PEDI-CAT (Mobility, Social/cognitive, and Responsibility). The section of Daily activities of PEDI-CAT demonstrated a statistically significant relationship with GMFM-88, PBS, 9-HPT, and grip strength for both upper extremities.

Results from stepwise linear regression analyses (Table 3) indicated that 9-HPT and grip strength significantly predicted Daily activities. In step 1, 9-HPT ($\beta=-.869$, $p=.000$) explained 75.5% of the 80.4% variance in Daily activity scores. The addition of grip strength ($\beta=.342$, $p=.031$) increased R^2 by 4.9%. Mobility performance was solely predicted by grip strength ($\beta=.773$, $p=.000$), accounting for 59.8% of the variance. The model gained for Social/cognitive ability was significantly predicted by 9-HPT alone ($\beta=-.762$, $p=.000$), which explained 58.1% of the variance. Responsibility performance was solely predicted by grip strength ($\beta=.843$, $p=.000$), accounting for 71.1% of the variance.

Discussion

The primary aim of this study was to determine which particular skills of motor and physical domains most contribute to functional performance measured by PEDI-CAT. Also, characteristics and inter-relatedness between variables of physical, motor, and functional domains were explored.

It was important to find a strong and statistically meaningful relationship between all 4 sections of PEDI-CAT and both of the variables linked to hand performance, dexterity, and grip strength in both hands. Stepwise regression analyses showed that 9-HPT, a measurement of dexterity, explained 75.5% of the variance in Daily activities section of PEDI-CAT, which increased to 80.4% when grip strength was added. Hence, dexterity and grip strength were found to be significant predictors of performance in Daily activities.

The 4 sections of PEDI-CAT also showed strong and significant associations with gross motor skills and balance. In line with our findings, Volman et al. [14] also found meaningful correlations between motor ability and functional skills, and also showed that motor ability (fine motor, ball skills, and balance combined) was a strong predictor of functional performance in 5–7-year-old children with DS.

As expected, all sections of PEDI-CAT were meaningfully inter-related. Based on conclusions of Dolva et al. [13] that performance of self-care activities in 5-year-old children with DS appeared most delayed in activities that required fine motor skills, and their recommendation to apply specific gross motor assessment instruments for a more precise description of the qualitative rather than functional characteristics of gross motor skills, our study looked into the relationship between fine and gross motor skills and functional performance, which showed in a very strong and significant correlation.

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Table 1. Demographic and clinical characteristics of participants.

Variables (n=44)		Mean	SD	SE	95% CI for mean Lower bound	95% CI for mean Upper bound	Min	Max
Sex								
Male	25 (56%)							
Female	19 (44%)							
Age (months)								
Male		140.67	48.03	9.42	121.27	160.07	59	227
Female		149.69	61.07	14.39	119.32	180.06	39	227
Hand dominance								
Right	29 (85%)							
Left	5 (15%)							
GMFM-88								
Male		93.81	6.55	1.28	91.17	96.46	77.06	100.00
Female		91.30	11.44	2.70	85.61	96.99	50.14	100.00
Total		92.79	8.85	1.33	90.10	95.47	50.14	100.00
PBS								
Male		51.00	5.27	1.05	48.82	53.18	32.00	56.00
Female		50.31	4.21	1.05	48.07	52.55	39.00	56.00
Total		50.73	4.84	.76	49.20	52.26	32.00	56.00
PEDI-CAT (T-score)								
Daily activities								
Male		22.45	10.77	2.30	17.68	27.23	10.00	46.00
Female		20.67	8.28	2.39	15.40	25.93	10.00	35.00
Total		21.82	9.87	1.69	18.38	25.27	10.00	46.00
Mobility								
Male		24.14	11.68	2.49	18.95	29.32	10.00	46.00
Female		19.25	9.91	2.86	12.95	25.55	10.00	39.00
Total		22.41	11.20	1.92	18.51	26.32	10.00	46.00
Social/cognitive								
Male		11.36	2.36	.503	10.32	12.41	10.00	18.00
Female		13.17	5.08	1.47	9.94	16.39	10.00	25.00
Total		12.00	3.59	.616	10.75	13.25	10.00	25.00
Responsibility								
Male		23.00	7.33	1.56	19.75	26.25	10.00	34.00
Female		22.25	8.60	2.48	16.78	27.72	12.00	38.00
Total		22.74	7.68	1.31	20.05	25.42	10.00	38.00

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Table 1 continued. Demographic and clinical characteristics of participants.

Variables (n=44)	Mean	SD	SE	95% CI for mean Lower bound	95% CI for mean Upper bound	Min	Max
9-HPT Right (s)							
Male	52.60	19.09	4.930	42.03	63.17	31.00	83.00
Female	42.00	14.57	4.207	32.74	51.26	31.00	83.00
Total	47.89	17.75	3.415	40.87	54.91	31.00	83.00
9-HPT Left (s)							
Male	57.50	21.65	5.59	45.51	69.49	33.00	100.50
Female	44.58	13.44	3.88	36.04	53.12	33.00	80.00
Total	51.76	19.28	3.71	44.13	59.39	33.00	100.50
Grip strength Right (kg)							
Male	11.50	6.90	1.84	7.51	15.49	1.00	22.00
Female	11.75	5.22	1.51	8.43	15.07	1.00	19.00
Total	11.62	6.07	1.19	9.16	14.07	1.00	22.00
Grip strength Left (kg)							
Male	8.86	5.46	1.46	5.70	12.01	0.00	18.00
Female	9.08	5.28	1.52	5.73	12.44	1.00	19.00
Total	8.96	5.27	1.03	6.83	11.09	0.00	19.00
BMI (kg/m^2)							
Male	19.08	4.61	1.03	16.92	21.24	13.90	28.88
Female	23.07	6.51	1.68	19.47	26.68	14.03	35.20
Total	20.79	5.77	.98	18.81	22.78	13.90	35.20

GMFM-88 – Gross Motor Function Measurement-88; PBS – Pediatric Balance Scale; PEDI-CAT – Pediatric Evaluation of Disability Inventory-Computer Adaptive Test; 9-HPT – Nine-Hole Peg Test; BMI – Body Mass Index.

9-HPT was found to be negatively correlated with grip strength for both upper extremities. This finding is contrary to the study of Priosti et al. [6], who also looked for correlations between grip strength and manual dexterity in the dominant hand of children with DS ages 7–9 years old, but did not find any such correlation.

9-HPT and grip strength of both extremities were significantly related with balance ability, and a higher correlation was found between grip strength and balance. This could be explained by an assumption that stronger muscles positively affect balance, while strength produced in the lower extremity is expected to also correspond with the strength in the upper extremity.

Low and insignificant associations between BMI and any of the other tested variables were observed in the present study, including gross and fine motor skills. Heterogeneous findings were encountered when we looked into similar studies in youngsters with and without intellectual disabilities. Comparable to our findings, no significant correlation was found between BMI and physical fitness and strength in youth with mild intellectual disabilities [26]. However, in typically developing preschool children BMI, a study found a significant correlation with gross motor tasks such as running, but no meaningful correlations were found with fine motor tasks [27].

The Daily activities section of PEDI-CAT, which assesses activities such as grooming, eating, dressing, activities related to household maintenance, and operation of electronic devices, showed with a somewhat lower than mean T-score than that for Mobility performance. The Mobility section of PEDI-CAT, including moving skills in different environments, such as the

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Table 2. Pearson correlation coefficients among all tested motor, functional, and physical parameters, including gross motor skills (GMFM-88), balance (PBS), functional skills (PEDI-CAT sections – daily activities, mobility, social/cognitive, and responsibility), dexterity (9-HPT), grip strength, and BMI measures.

Variables	1	2	3	4	5	6	7	8	9	10	11
GMFM-88											
R	1										
p value											
PBS											
R	.856**	1									
p value	.000										
Daily activities											
R	.754**	.727**	1								
p value	.000	.000									
Mobility											
R	.773**	.6 67**	.877**	1							
p value	.000	.000	.000								
Social cognitive											
R	.599**	.566**	.789**	.753**	1						
p value	.000	.000	.000	.000							
Responsibility											
R	.795**	.720**	.816**	.809**	.854**	1					
p value	.000	.000	.000	.000	.000						
9-HPT Right											
R	–.598**	–.555**	–.865**	–.667**	–.745**	–.774**	1				
p value	.001	.003	.000	.000	.000	.000					
9-HPT Left											
R	–.617**	–.530**	–.786**	–.635**	–.595**	–.668**	.880**	1			
p value	.001	.004	.000	.001	.002	.000	.000				
Grip strength Right											
R	.578**	.711**	.804**	.758**	.671**	.814**	–.752**	–.674**	1		
p value	.002	.000	.000	.000	.000	.000	.000	.000			
Grip strength Left											
R	.463*	.659**	.752**	.747**	.619**	.716**	–.679**	–.683**	.870**	1	
p value	.017	.000	.000	.000	.001	.000	.000	.000	.000		
BMI											
R	–.269	–.105	.088	–.104	.117	.128	–.165	–.119	.231	.135	1
p value	.119	.562	.651	.592	.545	.509	.452	.589	.289	.540	

* $p<0.05$; ** $p<0.01$. GMFM-88 – Gross Motor Function Measurement-88; PBS – Pediatric Balance Scale; PEDI-CAT – Pediatric Evaluation of Disability Inventory-Computer Adaptive Test; 9-HPT – Nine-Hole Peg Test; BMI – Body Mass Index.

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Table 3. Regression models for daily activities, mobility, social/cognitive, and responsibility sections of PEDI-CAT.

Step	F	Df	Beta	p Value
Daily activities				
I	67.69	1, 22		
9-HPT			–.869	.000
R^2=.755				
II	43.18	2, 21		
9-HPT			–.609	.000
Grip strength			.342	.031
ΔR^2=.044				
Final model R^2=.804				
Mobility				
I	28.24	1, 19		
Grip strength			.773	.000
Final model R^2=.598				
Social/cognitive				
I	26.39	1, 19		
9-HPT			–.762	.000
Final model R^2=.581				
Responsibility				
I	46.72	1, 19		
9-HPT			.843	.000
Final model R^2=.711				

PEDI-CAT – Pediatric Evaluation of Disability Inventory-Computer Adaptive Test; 9-HPT – Nine-Hole Peg Test.

ability to get in and out of bed or to get on and off the public bus, appeared to be the strongest advantage of functional domain in our participants, as it presented with the highest T-score, an observation similarly reported by Volman et al. [14].

On the other hand, weakest functional performance in the present study was depicted in the Social/cognitive section of PEDI-CAT, which assessed attention, communication, interaction, behavior, safety, play, and problem-solving skills needed for participation in family and community. The Responsibility section of PEDI-CAT measured the degree to which participants managed life tasks, which are of importance in transition to adulthood and independent living skills such as fixing a meal, planning and following a weekly schedule, health management, safety, and use of public transportation.

Our sample was relatively small, considering the large age-span of participants. The sample was also unequal in sex distribution, as males accounted for 56% of our entire sample.

Another limitation of this study is absence of cognitive performance examination of participants. Nevertheless, as previous studies showed that functional activities of children with DS were better predicted by the level of motor ability than by the level of performance mental ability [14], we considered the cognitive input was not of crucial importance in the functional domain. Another limitation of this study is the absence of prior translation of PEDI-CAT into Albanian language, which should be considered for future research.

We recommend that future studies include larger numbers of participants grouped into narrower intervals of age, which would strengthen the understanding of the relationship of functional performance with other domains of child development across different age periods. Hence, we suggest employing longitudinal studies in which the same children would be followed and assessed from childhood through adolescence.

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This study adds to understanding of the sources of disability and provides guidance in shaping intervention programs to improve functional performance. The information obtained is relevant to parents and those managing children with DS, especially physical and occupational therapists, physical education teachers, and medical professionals, as well as policy makers and service planners.

Conclusions

In summary, the results of the present preliminary study indicate fine motor skills and grip strength are significant predictors of performance of daily activities, and suggests that researchers should regard these skills as a prerequisite and a support to mastering daily activities in youth with DS. The outcomes from the present study also showed that mobility proficiency was the participants' strongest asset in the functional domain.

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