# Measurement of Performance of Basic Daily Skills and Assessment of Motor Function of Filipino Adolescent and Adult Persons with Down Syndrome

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## ABSTRACT

Objectives. This study was conducted to measure the performance in activities of daily living and to assess the motor function of adolescent and adult persons with Down syndrome.

Methods. Member families of the Down Syndrome Association of the Philippines, Inc. (DSAPI) were contacted for inclusion of adolescents and adults into the study. There were 12 adolescents and 7 adults who participated in the study. The functional status was assessed using the Functional Independence Measure (FIM) Instrument. Scores were given based on the answers of parents/guardians/caregivers. The ability to perform other daily living skills was assessed using a checklist, the Instrumental Activities of Daily Living (IADL). The motor function was assessed by evaluating the muscle strength (manual muscle testing); range of motion of joints (goniometer); and gait deviation while the subjects were walking. Subjects also underwent a complete physical and neurologic evaluation.

Results. Both adolescent and adult subjects with Down Syndrome in this study were functionally independent in locomotion and mobility. Lower scores were noted in terms of communication, social cognition skills and sphincter control. For self care, the patients were more independent in grooming, eating and upper garment dressing compared to bathing, lower garment dressing skills and toileting. Gross motor function was good in most patients. Adult subjects (FIM score 102-126) performed better than their adolescent counterparts (FIM score 81-126). The lowest FIM score was noted in the youngest subject. For the motor function, all subjects were ambulatory and able to perform kicking, standing on tiptoes and on heels; muscle strength assessed by manual muscle testing was normal in almost all the subjects; range of motion of joints was normal in majority of subjects but a significant number had limited movement at the ankle joints; and in doing instrumental activities of daily living skills (IADLS), majority of subjects were independent.

Conclusion. All the adolescent and adult subjects in the study were independent in locomotion and mobility using the FIM instrument. Motor function based on the results of the manual muscle testing and performance of instrumental activities of daily living (ADL's) in some household chores were good in both adolescents and adult subjects.

*Key Words: Down Syndrome, motor function, functional independence measure (FIM)*

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## Introduction

Down syndrome is the most common identifiable genetic cause of mental retardation and its incidence increases with increasing maternal age.[1] The degree of mental retardation that accompanies Down syndrome varies widely, ranging from mild to moderate to severe.[2,3] Generally, there is no way to predict the mental development of a child with Down syndrome based on physical features, however, it is speculated that the physical features may explain poor motor performance.[4]

Down syndrome affects approximately 1 in 800 to 1 in 1000 babies.[5] The Down Syndrome Association of the Philippines, Inc (DSAPI) has a membership consisting of 1350 families.[6]

Care for patients with chronic disability such as mental handicap constitutes a significant portion of health care costs, which include not only the direct costs of health care but also indirect costs incurred from limitation of patients and added cost for hired caregivers, particularly if the patient requires constant supervision. With the improvement in medical management of neonatal conditions, there is increased survival of children with chronic disabilities. It is for these reasons that assessment of a patient's independence in daily skills becomes relevant.[7] An assessment of this kind will aid in counseling of parents and in planning interventions.[8]

Motor function is one of the most frequently tested predictors of independence in daily living. Children with Down syndrome had much lower scores in motor proficiency tests compared to age-matched controls.[9] Fine motor skills were found to be more affected than gross motor functions. Patients with Down syndrome were also found to have the most difficulty with tasks requiring bimanual coordination.[6] Acquisition of expected motor skills is significantly delayed in children with Down syndrome. The rate of acquisition is much more varied than the upper limit of motor function achieved. The rate of motor development has been noted to decline with age due to increasing complexity of tasks, but most patients eventually achieve the function expected for the degree of disability.[8]

Other domains affecting daily functioning that have been studied include communication, adaptive social skills, memory function and performance of daily living skills. Expressive language is more affected than receptive language. Development of adaptive behavior has been

shown to be age-related during childhood. No such relation was observed in older patients with Down syndrome.[10]

Turner et al. studied the factors affecting self-sufficiency in children with Down syndrome. Mental age, excitability, behavioral problems, the extent by which the mother used practical means of coping and the level of the child's social activity were found to be the most important predictors of independence in these children.[11] Among elderly persons with Down syndrome, visual, cognitive and sensory impairment are other factors contributing to the level of performance.[12]

The objectives of the study were to measure the performance of activities of daily living and to assess the motor function of adolescent and adult persons with Down syndrome.

## Materials and Methods

*Subjects*. Member families of the DSAPI with adolescents and adults were contacted. Consent was obtained from the parents or guardians. The subjects attended a clinic where they were examined by one of the authors (SI). Parents/caregivers of the subjects were interviewed as to the various abilities of the patients to perform activities of daily living skills.

*Methods*. The functional status of the subjects were assessed using the Functional Independence Measure (FIM) Instrument.[13] It is a 7-level scale which determines the ability of the subject to carry out a task with or without the assistance of another person (Table 1). Scores were given based on the answers of the parent or the caregiver. The questionnaire is a set of 18 items subdivided into 6 groups: self care activities, sphincter control, mobility, locomotion, communication and social cognition. The scores of the 18 items were added.

**Table 1.** Scoring for levels of ability to perform tasks

| FIM Score | Ability to perform tasks |
|---|---|
| 7 | Subject can perform the task independently without any help |
| 6 | Subject can perform the task independently with an assistive device |
| 5 | Subject can perform the task with supervision |
| 4 | Subject can perform the task with minimal assistance |
| 3 | Subject can perform the task with moderate assistance |
| 2 | Subject can perform the task with maximal assistance |
| 1 | Subject needs total assistance in performing a task |

To assess the ability to perform other daily living skills, a checklist called the Instrumental Activities of Daily Living (IADL) was used.

To assess the motor function, muscle strength was evaluated by doing a Manual Muscle Testing (Classification of the Medical Research Council)[14] and the range of motion of the joints was measured using a goniometer. Gait deviations were noted while patient walked on a smooth level ground.

Subjects also underwent a complete physical and neurologic evaluation.

## Results

A total of 19 subjects were included in the study from an initial list of 21. Two subjects were excluded because of incomplete data in their evaluation forms. Of the 19 subjects, 11 were males and 8 were females, 12 of them were adolescents (between 12 to 18 years of age) and 7 were adults.

Majority of the subjects were found to be independent in the performance of daily activities of living as manifested by a score of 6 and 7 on the FIM. Table 2 shows the distribution of subjects based on their FIM scores in performing activities of daily living.

Table 3 shows the number of adolescents and adults performing activities of daily living independently and dependently.

For the motor function, all subjects were able to walk on the ground and stairs without any assist. They were all community ambulators. They were also able to perform the following tasks: kicking, standing on tiptoes and standing on heels.

Manual muscle testing using the Classification of Medical Research Council (MRC) was found to be normal in almost all of the subjects (Table 4).

Grip strength measured grossly was found to be good in 17 out of 19 subjects with the remaining 2 having a poor to fair grip strength.

Although majority of the subjects exhibited normal ranges of motion in the joints tested, a significant number showed limitation in the range of motion of the ankle joint (Table 5).

For the two patients with abnormal range of shoulder motion, one had limited shoulder flexion and one had limited shoulder abduction. Among patients with abnormal ankle motion, six had limited ankle dorsiflexion and eversion, four with limited ankle dorsiflexion only and one with limited ankle dorsiflexion, inversion and eversion.

Another measure of motor function was their ability to perform instrumental activities of daily living skills (IADLs). A checklist on ability to do household chores such as cleaning and tucking away clothes were included (Table 6).

Majority of the subjects were independent in doing the IADLs. Other subjects though, were not given the opportunity to do these chores by their parents or caregivers, and as a result, five were not given a chance to sort clothes, five did not fold clothes, four did not store clothes, three did not mop the floor and one did not dust the furniture.

## Discussion

Majority of the subjects in the study whether adolescents or adults were functionally independent with FIM score of 6-7 in most activities of daily living. They were all independent in transfers and in walking on level ground,

**Table 2.** Distribution of subjects based on ability in performing ADLs using the 7-point scale of the Functional Independence Measurement (FIM)

| Activities of daily living skills | FIM Score* | | | | | | |
|---|---|---|---|---|---|---|---|
| | 7 | 6 | 5 | 4 | 3 | 2 | 1 |
| Self-care | | | | | | | |
| Eating | 17 | 1 | 1 | 0 | 0 | 0 | 0 |
| Grooming | 14 | 1 | 2 | 1 | 0 | 1 | 0 |
| Bathing | 11 | 0 | 6 | 1 | 0 | 1 | 0 |
| Dressing - Upper Body | 14 | 1 | 0 | 4 | 0 | 0 | 0 |
| Dressing – Lower Body | 13 | 1 | 1 | 4 | 0 | 0 | 0 |
| Toileting | 10 | 1 | 2 | 5 | 1 | 0 | 0 |
| Sphincter control | | | | | | | |
| Bladder management | 15 | 3 | 1 | 0 | 0 | 0 | 0 |
| Bowel management | 18 | 0 | 0 | 0 | 0 | 0 | 1 |
| Mobility | | | | | | | |
| Bed, chair, wheelchair | 19 | 0 | 0 | 0 | 0 | 0 | 0 |
| Toilet | 19 | 0 | 0 | 0 | 0 | 0 | 0 |
| Tub, shower | 19 | 0 | 0 | 0 | 0 | 0 | 0 |
| Locomotion | | | | | | | |
| Walk/wheelchair | 19 | 0 | 0 | 0 | 0 | 0 | 0 |
| Stairs | 17 | 2 | 0 | 0 | 0 | 0 | 0 |
| Communication | | | | | | | |
| Comprehension | 8 | 4 | 1 | 6 | 0 | 0 | 0 |
| Expression | 6 | 4 | 1 | 8 | 0 | 0 | 0 |
| Social cognition | | | | | | | |
| Social interaction | 10 | 2 | 4 | 3 | 0 | 0 | 0 |
| Problem solving | 12 | 3 | 1 | 1 | 1 | 0 | 1 |
| Memory | 9 | 1 | 0 | 4 | 1 | 0 | 4 |

*1 being totally dependent and 7 being totally independent

**Table 3.** Comparison of the number of adolescents and adults in performing Activities of Daily Living (ADL)

| Activities of daily living | Number of Adolescents | | Number of Adults | |
|---|---|---|---|---|
| | Independent Performers | Dependent Performers | Independent Performers | Dependent Performers |
| Self care | | | | |
| Eating | 11 | 1 | 7 | 0 |
| Grooming | 10 | 2 | 5 | 2 |
| Bathing | 5 | 7 | 6 | 1 |
| Dressing – Upper | 9 | 3 | 6 | 1 |
| Dressing – Lower | 7 | 5 | 7 | 0 |
| Toileting | 6 | 6 | 5 | 2 |
| Sphincter control | | | | |
| Bladder management | 8 | 4 | 7 | 0 |
| Bowel management | 11 | 1 | 7 | 0 |
| Mobility | | | | |
| Bed, chair, wheelchair | 12 | 0 | 7 | 0 |
| Toilet, tub, shower | 12 | 0 | 7 | 0 |
| Locomotion | | | | |
| Walk/wheelchair | 12 | 0 | 7 | 0 |
| Stairs | 12 | 0 | 7 | 0 |
| Communication | | | | |
| Comprehension | 8 | 4 | 7 | 0 |
| Expression | 6 | 6 | 4 | 3 |
| Social cognition | | | | |
| Social interaction | 7 | 5 | 5 | 2 |
| Problem solving | 8 | 4 | 7 | 0 |
| Memory | 6 | 6 | 4 | 3 |

**Table 4.** Distribution of subjects according to their muscle strength

| Manual Muscle Test | Number of patients | |
|---|---|---|
| | Normal* | Abnormal* |
| Scapula | 18 | 1 |
| Shoulder | 18 | 1 |
| Elbow | 18 | 1 |
| Forearm | 18 | 1 |
| Wrist | 18 | 1 |
| Hip | 17 | 2 |
| Knee | 17 | 2 |
| Ankle | 16 | 3 |
| Toe | 17 | 2 |

*Normal signifies motor strength of 4/5 to 5/5;
Abnormal if motor strength is below 4/5

**Table 5.** Distribution of subjects according to the Range of Motion of Joints in both upper and lower extremities

| Joint | Number of patients | |
|---|---|---|
| | Normal* | Abnormal* |
| Shoulder | 17 | 2 |
| Elbow | 19 | 0 |
| Forearm | 19 | 0 |
| Wrist | 19 | 0 |
| Hip | 19 | 0 |
| Knee | 19 | 0 |
| Ankle | 8 | 11 |

* See Appendix for normal range of motion

**Table 6.** Distribution of subjects according to ability to perform Instrumental Activities of Daily Living Skills independently or dependently

| Number of patients | | |
|---|---|---|
| | Independent* | Dependent* |
| Clothing | | |
| Sorting | 14 | 0 |
| Folding | 13 | 1 |
| Storing | 15 | 0 |
| Cleaning | | |
| Picking up | 17 | 2 |
| Putting away | 17 | 2 |
| Sweeping | 16 | 3 |
| Mopping | 12 | 4 |
| Dusting | 15 | 3 |

and in climbing up and descending the stairs which fell under the category of locomotion and mobility in the FIM. It should be noted that the FIM score only determines the subject's dependence or independence on a helper to perform a task. It does not take into consideration the manner by which it was performed and whether it was done in a smooth or awkward manner. On further examination of the subjects, there was note of abnormalities in the gait such as the presence of a wide based gait and a decrease in the step length. It may be inferred therefore that there were subjects who had problems in balance and coordination and some with visual or perceptual impairment. It has been noted in several studies with Down syndrome that these problems indeed existed.[6,9] Although these impairments may be present in the subjects, they were not severe enough to cause a disability in this particular aspect of daily living skills. Likewise, the presence of abnormalities in the motor strength of the lower extremities in some subjects did not seem to affect attainment of independence in locomotion and mobility. A possible explanation for this is the inclusion of subjects with a motor strength of 3/5 (which means that the muscle can move against gravity) in the abnormal group. Moreover, the limitation in the range of motion of the ankle in 11 out of 19 subjects did not seem to hamper the patients' ability to ambulate.

High FIM scores were obtained in feeding, grooming and upper garment dressing. Subjects were able to perform IADLs on some household chores like cleaning. These findings suggest not only the presence of a good gross motor hand function but also the presence of cognitive skills which involve understanding and following of instructions, and ability to recall to be able to do the tasks repeatedly. Fine motor function of the hand will be better assessed though by observing the manner by which subjects performed the task so that one can check on the timing, the efficiency, the smoothness and the coordination of the movements.[15]

All the adult subjects were independent in bladder and bowel management. On the other hand, there were adolescents who were still dependent in these aspects of daily living skills. More adolescent subjects achieved better bowel than bladder control. This finding is in contrast to the usual development seen in children wherein daytime bladder control usually precedes bowel control.[16] Dependence in bladder and bowel management in adolescents may also be explained by the lower score achieved in expressive communication. It has been noted in other studies that toilet training requires the ability to verbalize bodily needs.[16]

With regards communication skills, all the adults were independent particularly in comprehension skills. Lower scores in ability to express oneself were seen in almost 50% of both the adult and adolescent groups. This weakness in expressive skills was also noted in other studies. This problem involving expressive communication may not only affect bladder and bowel management but it can affect the ability to interact with others.[10]

Only five subjects gathered low scores (FIM scores of 1 and 2) in bowel management, skill in problem solving and on recall. Only one subject obtained low scores in both problem solving and recall skills. This particular subject happened to be the youngest in the group being 15 years old only. It has been shown that children with DS may develop their cognitive skills with time.[10] It is therefore possible that this particular subject will be able to develop the skills as he gets older.

Comparing the total FIM scores of each adolescent and adult subject, the adolescent group obtained a lower score of 81. This was again noted in the youngest subject. The

lowest score in the adult group was 102. All the adolescent subjects were independent in locomotion and mobility. All the adult subjects were likewise independent in these as well as in bladder and bowel management, eating, and lower garment dressing. The latter skills may eventually also be achieved by the younger subjects as they grow older.[8] It has been shown that young children with Down syndrome may have a delay in the acquisition of gross motor skills and more time may be required in learning to perform certain movements.[8,9]

The total scores of the subjects in both the adolescent and the adult group ranged from 81 to 126. Perfect score of 126 was achieved in 2 out of 19 (10.5 %) subjects. There were 5 (26.3 %) with scores from 120 to 124. High scores achieved may be attributed to the fact that the subjects were all members of a support group. One can therefore assume that the parents and family have a higher level of awareness and understanding of the condition of the subjects. They may also have a positive attitude and more effective copings skills so that they are able to provide more learning experiences and support for the subjects.[17] It is worthy to note that 4 subjects had exposure to a Rehabilitation Program consisting of all or a combination of physical therapy, occupational therapy and speech therapy. The FIM scores achieved ranged from 98 to 126.

## Conclusion and Recommendations

Both adolescent and adult subjects with Down syndrome in this study were functionally independent in locomotion and mobility. Lower scores were noted in terms of communication, social cognition skills and sphincter control. For self care, the patients were more independent in grooming, eating and upper garment dressing compared to bathing, lower garment dressing skills and toileting. Gross motor function was good in most patients.

It is recommended that for future studies, a larger group of adolescent and adult subjects who do not belong to support groups be included. For the functional assessment, actual performance of the task should be done rather than rely on the answers given by the caregivers. Quality of the performance of the task should be included to determine how efficient and effective the subject is especially in accomplishing tasks requiring gross motor and fine hand functions.

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## References

1. Hunter AGW. Down Syndrome. In: Cassidy SB, Allanson JE, eds. Management of Genetic Syndromes, 2nd ed. John Wiley & Sons, Inc., 2005: 191-210.
2. Parikh AP, Goyel NA. Mental performance in Down Syndrome. Indian J Pediatr. 1990; 57:261-263.
3. March of Dimes. Down Syndrome. Available at http://www.marchofdimes.com/pnhec/4439_1214.asp. Accessed January 22, 2009.
4. Spano M, Mercuri E, Rando T, et al. Motor and perceptual-motor competence in children with Down Syndrome: variation in performance with age. Eur J Pediatr Neurol. 1999; 3(1):7-13.
5. Mange EJ, Mange AP. Basic Human Genetics. Sinauer Associates, Inc., 1994: 215.
6. Down Syndrome Association of the Philippines, Inc. Available at http://www.dsapi.org/staticpages/index.php?page=FAQ. Accessed January 22, 2009.
7. Msall, M. Tools for measuring daily activities in children: promoting independence and developing a language for child disability. Pediatrics. 2002 Feb;109(2):317-9.
8. Palisano RJ, Walter SD, Russell DJ, et. al. Gross motor function of children with Down Syndrome: creation of motor growth curves. Arch Phys Med Rehabil. 2001 Apr;82(4):494-500.
9. Connolly BH, Michael BT. Performance of retarded children with and without Down Syndrome, on the Bruininks Oseretsky Test of Motor Proficiency. Phys Ther. 1986 Mar; 66(3):344-8.
10. Dykens EM, Hodapp RM, Evans DW. Profiles and development of adaptive behavior in children with Down Syndrome. Am J Ment Retard. 1994 Mar;98(5):580-7.
11. Turner S, Sloper P, Knussen C, Cunningham C. Factors relating to self-sufficiency in children with Down Syndrome. J Ment Defic Res. 1991 Feb;35(Pt 1):13-24.
12. Roeden JM, Zitman FG. Ageing in adults with Down Syndrome in institutionally based and community-based residences. J Intellect Disabil Res. 1995 Oct;39 (PT 5):399-407.
13. Christiansen C, Ottenbacher K. Evaluation and management of daily self care requirements. In: De Lisa J, Gans B, eds. Rehabilitation Medicine: Principles and Practice, 3rd ed. Lippincott- Raven Publishers, Inc, 1998. 7:138 -147.
14. Frontera WR, Lexell J. Assessment of Human Muscle Function. In: de Lisa Joel A, Gans B, Walsh NF, eds. Physical Medicine and Rehabilitation: Principles and Practice, 4th ed. Lippincott Williams and Wilkins, 2005.5:143.
15. Exner, Charlotte E. Development of Hand Skills. In: Case-Smith J, ed. Occupational Therapy for Children, 1st ed. Mosby, Inc, 2001. 11:289 – 312.
16. Needlman, RD. Preschool Years. In: Kliegman RM, Behrman RE, Stanton BF, Jenson HB, eds. Nelson Textbook of Pediatrics, 17th ed. Saunders, 2004. 12: 44.
17. Serr J, Mandleco B, Olsen S, Dyches T. Caregiver burden and depression in parents raising children with disabilities/chronic conditions. Available at http://nursing.byu.edu/Documents/research/abstracts_05-06/Serr,%20Mandleco,%20Olsen,%20Dyches%20(2006)%20CAREGIVER%20BURDEN%20AND%20DEPRESSION%20IN%20PARENTS%20RAISING.pdf. Accessed January 22, 2009.
18. Ganter BK, et al. Priniciples of Evaluation and Management. In: de Lisa Joel A, Gans B, Walsh NF, eds. Physical Medicine and Rehabilitation: Principles and Practice, 4th ed. Lippincott Williams and Wilkins, 2005. 1:12-19.

## Appendix

**Normal range of motion of joints[18]**

| Joint | Motion | Normal Values |
|---|---|---|
| Cervical | Flexion | 0-45° |
| | Extension | 0-45° |
| | Lateral rotation | 0-60° |
| | Lateral bending | 0-45° |
| Shoulder | Flexion | 0-180° |
| | Extension | 0-60° |
| | Abduction | 0-180° |
| | Internal rotation | 0-90° |
| | External rotation | 0-90° |
| Elbow | Flexion | 0-150° |
| | Extension | 0-150° |
| Forearm | Pronation | 0-90° |
| | Supination | 0-90° |
| Wrist | Flexion | 0-80° |
| | Extension | 0-70° |
| | Radial deviation | 0-20° |
| | Ulnar deviation | 0-30° |
| Hip | Flexion | 0-120° |
| | Extension | 0-10° |
| | Abduction | 0-45° |
| | Adduction | 0-30° |
| | External rotation | 0-45° |
| | Internal rotation | 0-45° |
| Knee | Flexion | 0-135° |
| | Extension | 0-135° |
| Ankle | Dorsiflexion | 0-20° |
| | Plantarflexion | 0-40° |
| | Inversion | 0-35° |
| | Eversion | 0-35° |