Objectives. The purpose of this study was to describe home and community functional performance in 5-year-old children with Down syndrome.

Method. In a cross-sectional study of 5-year-old children with Down syndrome in Norway (N = 43), functional performance was measured with the Norwegian translation of the Pediatric Evaluation of Disability Inventory (PEDI). Additional descriptive information related to health, disabilities, and function was also gathered.

Results. The children showed a wide range of functional performance. Performance of self-care activities appeared most delayed on activities that required fine motor skills. Children appeared less affected in basic functional mobility skills. Parents identified their main concerns as language functioning and, for the children not yet toilet trained, the management of bladder and bowel control in relation to starting school.

Conclusion. The results provide baseline information regarding typical levels of functional performance in children with Down syndrome at 5 years of age. However, the broad range of functional performance across children indicates a need for caution in generalizing the results to an individual child.

occupational therapy assessment of children ideally begins with investigation of the child’s level of participation in daily activities in relevant contexts (American Occupational Therapy Association, 2002; Case-Smith, 2001). With an understanding of the child’s participation, therapists continue the evaluation process to identify limitations in specific activities that may be impeding successful participation. This global to specific focus has been termed the “top-down” approach to identifying and understanding occupational performance difficulties (Holm, Rogers, & Stone, 1997; Trombly, 1993, 1995). Intervention is then designed to support developmentally and functionally higher activity performance in areas of greatest concern (Case-Smith, 2001).

When development is delayed, as is typical for children with Down syndrome (DS), families have many questions regarding what expectations are reasonable for their children. Caregivers want to know how their child is performing relative to expectations for children of the same age and disability, and want information that can help them set realistic goals for their child. Many of their questions relate to everyday functional performance, occupations, and participation. Meeting this need of families requires good descriptive information about the course of functional development in children with DS, which is the focus of the present study. Down syndrome is characterized by developmental delays in all areas of function, although the degree can vary greatly among individuals. Children with DS are just as different from one another as are all other children (Rogers, Gordon, Schanzenbacher, & Case-Smith, 2001). Much of the recent research with this population has focused on defining the underlying mental, motor, and neurophysiological deficits that may account for observed performance difficulties.
(Pennington, Moon, Edgin, Stedron, & Nadel, 2003; Spano et al., 1999). A smaller number of researchers have focused on describing the developmental trajectories of children with DS, or examining the extent to which children with DS follow the same general sequence of skill acquisition as typically developing children. The latter studies are the most directly applicable to intervention, as they provide guidelines regarding the expected timetables for development in particular areas, and profiles of typical strengths and weaknesses that can be used to focus intervention efforts.

The motor skills of children with Down syndrome have been studied in detail by physical therapy researchers (e.g., Connolly, Morgan, Russell, & Fulliton, 1993). For example, Palisano et al. (2001) used the Gross Motor Function Measure to construct growth curves for the motor development of children with DS from 1 month to 6 years. Their results indicated that the probability of walking increased from 40% at 24 months to 92% by 36 months, and the probability of running, walking upstairs, and jumping forward was only around 50% at 5 years.

A number of studies have found fine motor skills to be less affected than gross motor skills (Connolly et al., 1993). However, results from a recent study by Spano et al. (1999) indicated that all aspects of fine motor skills were severely impaired in their sample of children with DS, irrespective of age. The same study indicated that difficulty with fine motor skills was more disabling than limitations in gross motor skills and mobility. Lauteslager, Vermeer, and Holders (1998) have argued that the motor development of children with DS shows its own specific developmental course and, as a result, reference to normal developmental sequences cannot be justified.

Patterns of adaptive skills development have been the focus of several cross-sectional and longitudinal investigations. Dykens, Hodapp, and Evans (1994), examined patterns on the Vineland Adaptive Behavior Scales in a cross-sectional study of children with DS between the ages of 1 and 11 years. They reported a significant relative weakness in communication skills, specifically in expressive communication. Relative communication weakness has also been reported by other studies examining language specifically (e.g., Berglund, Eriksson, & Johansson, 2001; Fowler, Gelman, & Gleitman, 1994). Another cross-sectional study using the Functional Independence Measure for Children (WeeFIM) examined the acquisition of independence in basic ADL and mobility tasks in school-age children with DS (Mean age = 11.4 years) (Leonard, Msall, Tremont, Bower, & Leonard, 2002). Within this group, over half the children needed no help with the self-care tasks, and fewer than 10% required help with mobility tasks. However, more than half the children required help or supervision with communication and social cognition tasks such as social interaction and problem solving. Although these studies provide a general overview of functional skill development in DS, the data were not analyzed by age group and thus do not provide useful guides for assessment and intervention planning. All studies note the significant variation in ability levels within the group of children with DS.

In contrast to the cross-sectional studies reported above, Carr (1995) provided data from a longitudinal study of a sample of 54 British children with Down syndrome who were seen at 15 months, 4, 11, and 21 years. She reported that at 4 years of age none of the children consistently ate without some help, over half the group needed a significant amount of help with dressing, and 60% of the children were enuretic. She also noted that the timing of skill acquisition was very variable and was not well-predicted by IQ at the younger ages. It is important to note that this study was initiated in the 1960s, thus it is likely that early intervention services were not as available to the families as might be the case currently.

In sum, available data provide some indication of typical areas of strength and weakness, but knowledge about functional performance at specific ages in children with DS is limited. There is a need for more detailed information about mastery of skills that are important in daily life to help address family questions and to assist in planning effective intervention programs. The purpose of the present study was to describe functional performance in 5-year-old children with DS. The age of 5 years (60–72 months) was chosen because, for the majority of children, this period is immediately before the start of elementary school and thus is an important transition point. The study was intended to provide additional specific information about the typical level of skill mastery and need for assistance of children with DS to support more effective planning for these children and their families.

**Method**

**Participants**

From the total population of 50–70 children born yearly in Norway with DS, 62 children between the ages of 60 and 72 months were identified with help from local DS associations and the county child habilitation services. Parents were asked by letter to participate in the study by completing a structured interview with the researcher. Parent confidentiality was maintained by having the information letters sent through the associations, thus no information regarding the 19 parents who did not reply was accessible.
The PEDI is normed for children ages 6 months to 7 1/2 years. Support for the internal consistency, inter-interviewee and test–retest reliability, and discriminative validity have been reported in a number of research reports (Feldman, Haley, & Coryell, 1990; Haley, Coster, Ludlow, Haltiwanger, & Andrellos, 1992; Nichols & Case-Smith, 1996). The Norwegian translation of the PEDI (Jahnsen, Berg, Dolva, & Hoyem, 2000) was used in this study. Excellent support for the reliability of the Norwegian version of the PEDI was obtained in a study by Berg, Jahnsen, Frey Froislie, and Hussain (2004). The PEDI is in the process of being standardized on Norwegian children. The normative scores are presented, therefore, with caution due to potential cultural differences observed in the self-care and mobility domains by Berg, Frey Froislie, and Hussain (2003).

The PEDI Functional Skills scales measure the child’s ability to perform specific functional activities. Items are scored either 1 (child has the capability) or 0 (child is unable). The Caregiver Assistance scales measure the typical amount of assistance provided by the caregiver during completion of basic functional tasks in the areas of self-care, mobility, and social function (from independence = no physical assistance or supervision, through total assistance = caregiver does the entire task). Items are grouped into hierarchical sets of 5, from easiest to hardest, in each discrete task area. Summary raw scores from both sets of scales can be transformed into two types of standard scores: normative scores and scaled scores. Normative scores are age-based and provide an indication of the child’s level of functional performance relative to age expectations. Normative standard scores are t scores with a mean of 50 and a SD of 10. Scaled scores provide an indication of the child’s performance along a continuum of relatively easy to relatively difficult items in a particular domain. These scores provide an estimate of the current level of performance (regardless of age), on a scale from 0 to 100.

In addition to the PEDI, information was obtained regarding the child’s medical problems, and results of recent and previous interventions for each child. Parents were also asked in which situations their child performed well, and what situations were challenging regarding everyday functional performance.

### Data Analysis
Normative and scaled scores were calculated and descriptive statistics computed by both group and gender. Results of cognitive testing were not accessible, therefore a classification by general cognitive level was created from the PEDI data by using the Functional Skills normative standard scores in the Social Function domain. Previous research has reported a correlation of .88 between PEDI Social Function scores and cognitive level measured by the Battelle Developmental Inventory Screening Test (BDIST) in a study of children with disabilities (Haley et al., 1992). A pilot study of the applicability of the PEDI to Norwegian children found values in the social function domain similar to the U.S. reference values (Berg et al., 2003). Because the PEDI normative scores follow a normal distribution with a mean of 50, 95% of the children in each age group are expected to score within two SDs of the mean, that is between 30 and 70 (Haley et al.). Thus, a lower boundary set at –1.5 SD from the mean (i.e., a score of 35) could be used to identify the lowest 10% of the population, that is, those who would be identified as showing some degree of delay (Polgar & Thomas, 1995). Using this approach, the

---

**Table 1. Child Gender, Age, and Cognitive Rating Characteristics in (N = 43)**

<table>
<thead>
<tr>
<th>Age (in months)</th>
<th>Girls (n = 20)</th>
<th>Boys (n = 23)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean (SD)</td>
<td>65.9 (3.51)</td>
<td>64.9 (3.80)</td>
</tr>
<tr>
<td>Range</td>
<td>60–72</td>
<td>60–72</td>
</tr>
<tr>
<td>Cognitive level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Age appropriate</td>
<td>1</td>
<td>3</td>
</tr>
<tr>
<td>Mild delay</td>
<td>13</td>
<td>9</td>
</tr>
<tr>
<td>Moderate delay</td>
<td>6</td>
<td>11</td>
</tr>
</tbody>
</table>

---

for analysis by the researcher. Forty-three letters of consent were returned, which represents a response rate of 70%. Sample characteristics are presented in Table 1.

### Instrument
The Pediatric Evaluation of Disability Inventory (PEDI; Haley, Coster, Ludlow, Haltiwanger, & Andrellos, 1992) was chosen to gather information on functional mobility within the home and community environment, self-care activities such as dressing, toileting, and grooming, socialization with peers, and functional communication. The PEDI is a standardized parent interview that examines functional performance and the need for caregiver assistance in three domains: self-care, mobility, and social function. The PEDI is normed for children ages 6 months to 7 1/2 years. Support for the internal consistency, inter-interviewee and test–retest reliability, and discriminative validity have been reported in a number of research reports (Feldman, Haley, & Coryell, 1990; Haley, Coster, Ludlow, Haltiwanger, & Andrellos, 1992; Nichols & Case-Smith, 1996). The Norwegian translation of the PEDI (Jahnsen, Berg, Dolva, & Hoyem, 2000) was used in this study. Excellent support for the reliability of the Norwegian version of the PEDI was obtained in a study by Berg, Jahnsen, Frey Froislie, and Hussain (2004). The PEDI is in the process of being standardized on Norwegian children. The normative scores are presented, therefore, with caution due to potential cultural differences observed in the self-care and mobility domains by Berg, Frey Froislie, and Hussain (2003).

The PEDI Functional Skills scales measure the child’s ability to perform specific functional activities. Items are scored either 1 (child has the capability) or 0 (child is unable). The Caregiver Assistance scales measure the typical amount of assistance provided by the caregiver during completion of basic functional tasks in the areas of self-care, mobility, and social function (from independence = no physical assistance or supervision, through total assistance = caregiver does the entire task). Items are grouped into hierarchical sets of 5, from easiest to hardest, in each discrete task area. Summary raw scores from both sets of scales can be transformed into two types of standard scores: normative scores and scaled scores. Normative scores are age-based and provide an indication of the child’s level of functional performance relative to age expectations. Normative standard scores are t scores with a mean of 50 and a SD of 10. Scaled scores provide an indication of the child’s performance along a continuum of relatively easy to relatively difficult items in a particular domain. These scores provide an estimate of the current level of performance (regardless of age), on a scale from 0 to 100.

In addition to the PEDI, information was obtained regarding the child’s medical problems, and results of recent and previous interventions for each child. Parents were also asked in which situations their child performed well, and what situations were challenging regarding everyday functional performance.

### Procedure
The first author, who was specifically trained in administration of the PEDI, completed all the interviews. Twenty-two interviews were completed by personal meeting and 21 by phone. Of the interviewees, 38 were mothers, two were fathers, and three couples responded together. The opened-ended questions related to heath conditions, therapy, and what situations were found to be strengths or challenges were asked in the order listed, before the PEDI interview was conducted. The Regional Ethical Committee (Region East) in Norway approved the study.
range for the group categorized with “mild” delay was from –1.5 to –2.0 SDs (PEDI scores from 30 to 35), with the next lower group classified as “moderate” delay.

Scaled scores were used for all other analyses because they can be interpreted more directly in terms of actual item accomplishment (Coster, Mancini, & Ludlow, 1999). The Modification Scales were used to identify the number of functional tasks for which modifications or adaptations were routinely used.

The PEDI software program was used for scoring. Data from the PEDI and additional interview questions were analyzed using SPSS (version 10.0). An alpha level of $p < .05$ was set for all statistical comparisons (Polgar & Thomas, 1995).

Results

General Characteristics of the Sample

All 43 children included in the study lived with their families as part of a community, and participated in individual preschool intervention programs and kindergarten (Norwegian children start school the year they reach the age of 6). Gender, age, and cognitive rating characteristics of the children are presented in Table 1.

The cognitive rating showed a slight difference in the distribution by gender, with a greater percentage of boys in the moderate delay group. However, no statistically significant differences were found between the scores of girls and boys on any of the subsequent analyses.

The distribution of DS types was trisomy 21 (93%), mosaic type (5%), and translocation type (2%). The most common health impairments reported by parents were congenital heart conditions (56%), visual impairments (49%), and hearing impairments (30%).

Parents’ Perception of the Children’s Functioning

Typical well-functioning situations for the children, as reported by the parents, were eating (47%), playing alone or together with other children (40%), parts of dressing (31%), helping in ordinary family activities at home (23%), and technical activities such as computer games (19%). Speech and communication were reported as an area of difficulty for 54% of the children, toilet training for 47%, and social interaction with peers for 16%.

Performance on PEDI Functional Skills Scales

The children’s normative and scaled scores in self-care, mobility, and social functioning, subdivided by gender, are presented in Table 2. The percentage of children rated “capable” on the highest (most difficult) item in each area is given in Table 3.

The self-care domain covers eating, grooming, bathing, dressing upper and lower body, toileting, and bladder and bowel management. The result shows considerable variance, with the range even greater in girls than boys. The mean scaled score for the girls (61.7) was slightly higher than for the boys (58.4). Functional performance in self-care seems to become demanding when fine motor skills are required (see Table 3). When analyzing each item in the self-care domain, toileting tasks and management of bladder and bowel represent the lowest scores of functional performance in the sample. Girls were significantly ahead of boys in the development of bladder and bowel control, which also could explain the girls’ higher mean scaled score in the self-care domain. The first sign of gaining control was the capability (item) for indicating the need to be changed after bowel movements, and the second sign, the capability of indicating a wet diaper. This distinguishing capability, and the ability to occasionally indicate the need to use the toilet (daytime) were significantly related to the child’s ability to tell about their own feelings and thoughts, as indicated by this item from the Social Function domain ($\chi^2 = 6.435; df = 1; p = 0.033$), ($\chi^2 = 6.747; df = 1, p = 0.009$).

The mobility domain covers chair and toilet transfers, car transfers, bed mobility and transfers, bathtub transfers, indoor and outdoor locomotion, and stairs. Great variations were found within the group. Although boys had a slightly higher mean scaled score (77.1) than girls (74.9), this difference was not statistically significant. All 43 children were capable of outdoor and indoor locomotion. Walking up and down stairs was not reported to be a problem, except for those children who needed more time compared to their peers. Safe transfer in and out of an adult-sized bathtub was mastered by most of the children (77%), but a challenge for some. As is customary in Norway, most children used the shower more often than the bathtub. Most of the children were capable of climbing on and off an adult-sized toilet (74%). Getting in and out of a car, without assistance, was managed by most of the children (70%), although management of seatbelts and opening and closing car doors were still a challenge for most of them (86%).

The social function domain covers functional comprehension, functional expression, joint problem solving, peer play, and safety. The mean scaled scores and range in both gender groups were highly similar (girls 57.5; boys 57.0) (see Table 2). The mean score for the functional comprehension items in the group of children with DS was somewhat higher than the mean capability in functional expression. Most of the children needed prompting about safety rules when crossing the street with an adult. No child in the sample had learned safety rules about interacting with strangers. In addition, during the interview 14% of the...
Table 2. Means, Standard Deviations, and Ranges of Children’s \((N = 43)\) Normative and Scaled Scores on the Pediatric Evaluation of Disability Inventory (PEDI) Functional Skills Scales

<table>
<thead>
<tr>
<th>Normative scores</th>
<th>Scaled scores</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
</tr>
<tr>
<td>Self-care ((N = 43))</td>
<td>25.4</td>
</tr>
<tr>
<td>Girls ((n = 20))</td>
<td>27.4</td>
</tr>
<tr>
<td>Boys ((n = 23))</td>
<td>23.5</td>
</tr>
<tr>
<td>Mobility ((N = 43))</td>
<td>*</td>
</tr>
<tr>
<td>Girls ((n = 20))</td>
<td>*</td>
</tr>
<tr>
<td>Boys ((n = 23))</td>
<td>*</td>
</tr>
<tr>
<td>Social function ((N = 43))</td>
<td>27.4</td>
</tr>
<tr>
<td>Girls ((n = 20))</td>
<td>27.4</td>
</tr>
<tr>
<td>Boys ((n = 23))</td>
<td>27.3</td>
</tr>
</tbody>
</table>

Note. The PEDI does not provide normative score equivalents < 10, therefore 20 children with scores in that range were excluded from analyses (*). The remaining sample was too small to allow statistical analyses.

Table 3. Percentage of Children With Down Syndrome Reported Capable of Most Advanced Item in Each Functional Area

<table>
<thead>
<tr>
<th>% Capable</th>
<th>% Capable</th>
</tr>
</thead>
<tbody>
<tr>
<td>A. Food textures: Eats all textures of table food</td>
<td>83.7</td>
</tr>
<tr>
<td>B. Use of utensils: Uses a knife to butter bread, cut soft foods</td>
<td>34.9</td>
</tr>
<tr>
<td>C. Use of drinking containers: Pours liquid from carton or pitcher</td>
<td>37.2</td>
</tr>
<tr>
<td>D. Tooth brushing: Prepares toothbrush with toothpaste</td>
<td>11.6</td>
</tr>
<tr>
<td>E. Hair brushing: Manages tangles and parts hair</td>
<td>16.3</td>
</tr>
<tr>
<td>F. Nose care: Blows and wipes nose without request</td>
<td>39.5</td>
</tr>
<tr>
<td>G. Hand washing: Dries hands thoroughly</td>
<td>67.4</td>
</tr>
<tr>
<td>H. Washing body and face: Washes and dries face thoroughly</td>
<td>30.2</td>
</tr>
<tr>
<td>I. Pullover/front opening garments: Puts on/removes front-opening shirt, including fasteners</td>
<td>11.6</td>
</tr>
<tr>
<td>J. Fasteners: Zips and unzips, separates and hooks zipper</td>
<td>7</td>
</tr>
<tr>
<td>K. Pants: Puts on pants, including fastening</td>
<td>4.7</td>
</tr>
<tr>
<td>L. Shoes/socks: Ties shoelaces</td>
<td>0</td>
</tr>
<tr>
<td>M. Toileting tasks: Wipes self thoroughly</td>
<td>0</td>
</tr>
<tr>
<td>N. Bladder management: Consistently stays dry day and night</td>
<td>14</td>
</tr>
<tr>
<td>O. Bowel management: Takes self into bathroom, has no bowel accidents</td>
<td>30.2</td>
</tr>
</tbody>
</table>

Mobility

A. Toilet transfers: Gets on and off toilet, not needing arms | 11.5 |
B. Chair transfers: Gets in and out of chair, not needing arms | 25.5 |
C. Car transfers: Gets in and out of car; opens and closes car door | 18.6 |
D. Bed mobility/transfers: Gets in and out of own bed, not needing arms | 32.6 |
E. Tub transfers: Steps/transfers into and out of adult-sized tub | 77.6 |
F. Indoor locomotion methods: Walks without support | 97.7 |
G. Indoor locomotion distance/speed: Moves indoors 50 ft.; opens and closes doors | 100 |
H. Indoor locomotion pulls/carries objects: Carries fragile or spillable objects | 90.7 |
I. Outdoor locomotion methods: Walks without support | 100 |
J. Outdoor locomotion distance/speed: Moves 150 ft. and longer, no difficulty | 100 |
K. Outdoor locomotion surfaces: Up and down curbs | 100 |
L. Upstairs: Walks up entire flight, no difficulty | 14 |
M. Downstairs: Walks down full flight, no difficulty | 11.6 |

Social Function

A. Comprehension—word meanings: Understands talk about time and sequence | 76.6 |
B. Comprehension sentence complexity: Understands two sentences about same subject, with different form | 55.8 |
C. Functional use of communication: Tells about own feelings or thoughts | 51.2 |
D. Complexity of expressive communication: Connects two or more thoughts to tell a simple story | 39.5 |
E. Problem resolution: With ordinary problem, can join adult to work out solution | 39.5 |
F. Social interactive play (adults): During play, suggests new or different steps | 76.7 |
G. Peer interaction: Plays activities or games that have rules | 30.2 |
H. Play with objects: Makes up elaborate pretend sequences from imagination | 60.5 |
I. Self-information: Can direct adult to help him/her return home | 7 |
J. Time orientation: Keeps track of schedule (using clock or asking others) | 0 |
K. Household chores: Consistently initiates and carries out task with steps | 0 |
L. Self-protection: Crosses busy street safely without adult | 0 |
M. Community function: Makes transaction in neighborhood store | 7 |

*Less than 50% of children in the normative sample were reported to be capable of this item at 5 years 0 months of age. For further details, see the PEDI Manual.
Parents reported being challenged by their children running away when they are outside.

**Performance on PEDI Caregiver Scales**

Parents’ rating of the level of assistance typically provided to the child for each functional task showed considerable variation in all domains (see Table 4). However, no statistically significant gender differences were found.

The mobility domain had the highest mean scaled score (82.9), indicating limited need for assistance during functional performance of these tasks. The self-care domain had a mean scaled score of 56.2 and showed considerable variation in almost all items (areas), with greatest independence in eating, and a considerable need for caregiver assistance in bowel and bladder management. The social function mean scaled score (60.2) showed less variation than mobility and self-care, and all item means were in the moderate to minimal assistance range. No differences were found between genders (see Table 4). The children were reported to use ordinary child equipment (such as a step stool in front of the toilet), if any, on the Modifications section of the PEDI.

**Other Factors Influencing Functional Performance**

Further analyses were undertaken to examine other factors potentially related to functional performance in this sample of children with DS, including medical conditions and intervention experience. The mean Functional Skills scaled scores in all three domains were slightly lower for children with heart conditions compared to children without heart defects. However, there were no statistically significant relationships between functional performance and type of DS, or presence of heart defects, vision, hearing, or other impairments.

Children were receiving a variety of regular interventions such as orofacial regulation therapy (49%) (variations of the method developed by R. Castillo Morales) (Castillo Morales, Brondo, & Haberstock, 1998), gross motor and mobility training (28%), and sensorimotor stimulation (23%). Regular interventions are usually provided by assistants, preschool teachers, physiotherapists, or occupational therapists, often under supervision of specialists. The only statistically significant finding, when analyzing previous and present intervention in relation to functional performance skills, was that children given orofacial regulation therapy were significantly more likely to have mastered management of all kinds of food texture ($\chi^2 = 3.995; df = 1; p = 0.046$).

**Discussion**

Consistent with other reports in the literature, this group of 5-year-old children with DS showed considerable variation in functional performance skills, cognitive level, and need for caregiver assistance. However there were also some consistencies across children. These results provide valuable information for practitioners and families regarding both the typical level of functional skill development for this group of children, and the extent of variation seen in different skill areas. The findings expand the limited information previously available to families regarding what to expect at this age, and provide guidance for setting realistic goals during intervention planning.

In the domain of self-care, management of bowel and bladder (toilet training) was an area of considerable concern for the parents. More than $1/4$ of the children in this study used diapers daily and parents reported worry regarding starting school and social stigmatization. Previous studies of children without disabilities have indicated that girls are trained an average of 2.5 months earlier than boys, and that bowel control precedes bladder control (Shepherd, 2001). A recent study (Schum et al., 2002) noted that the age of daytime bowel and bladder control has steadily increased

---

**Table 4. Means, Standard Deviations, and Ranges of Children’s ($N = 43$) Normative and Scaled Scores on the Pediatric Evaluation of Disability Inventory (PEDI) Caregiver Assistance Scales**

<table>
<thead>
<tr>
<th>Domain</th>
<th>Normative scores</th>
<th>Scaled scores</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>Mean</td>
<td>SD</td>
</tr>
<tr>
<td>Self-care (N = 43)</td>
<td>26.7*</td>
<td>6.8*</td>
</tr>
<tr>
<td>Girls (n = 20)</td>
<td>27.4*</td>
<td>6.8*</td>
</tr>
<tr>
<td>Boys (n = 23)</td>
<td>26.1*</td>
<td>6.8*</td>
</tr>
<tr>
<td>Mobility (N = 43)</td>
<td>37.4**</td>
<td>12.8**</td>
</tr>
<tr>
<td>Girls (n = 20)</td>
<td>35.8**</td>
<td>13.4**</td>
</tr>
<tr>
<td>Boys (n = 23)</td>
<td>38.9**</td>
<td>12.4**</td>
</tr>
<tr>
<td>Social Function (N = 43)</td>
<td>31.5***</td>
<td>8.5***</td>
</tr>
<tr>
<td>Girls (n = 20)</td>
<td>30.6***</td>
<td>7.0***</td>
</tr>
<tr>
<td>Boys (n = 23)</td>
<td>32.2***</td>
<td>9.7***</td>
</tr>
</tbody>
</table>

Note. The PEDI does not provide normative score equivalents < 10. Thus, 2 boys (*), 2 girls, and 3 boys (**) and 1 girl and 1 boy (***) with scores < 10 were excluded from the analyses.
from approximately 24 months in the 1950s to 36 to 39 months in the late 1990s for children without disabilities. Clinical literature indicates that most children with DS stay dry day and night by 4–5 years of age, which is about 1 year delayed (Annerén, Johansson, Kristiansson, & Lööw, 1997; Lofterod, 1989). However, Carr (1995) reported that in her longitudinal study, only 35% of the children with DS were toilet trained at age 4, and, at 11 years, one third were still enuretic. Children with mental retardation generally take a longer period to learn toileting skills. Problems with awareness, initiation, sequencing, memory, and dexterity in managing their clothes are typical. As with all children, physiological readiness for toileting is a prerequisite before beginning training programs (Shepherd, 2001). The data from this study suggest that children with DS follow the typical developmental sequence and gender differentiated pattern, but on a delayed timetable. There appeared to be a relationship between being able to distinguish between the need for urination and for defecation and the cognitive ability to talk about one’s own feelings and thoughts for these children. This finding may reflect the complexity of this area of function, and the potential relevance of body awareness and sensory integration for skill mastery. More research is needed to understand the delay of bladder and bowel control in children with DS, and to be able to give support to parents in this matter.

Many studies have reported motor impairment in children with DS, and have suggested that fine motor skills may be less affected than gross motor skills (Connolly et al., 1993). However, the findings of this study support the conclusions by Spano et al. (1999) that poor fine motor skills may be disabling in this population, for example, by affecting performance of complex self-care tasks that involve fine motor skills, such as the capability of using knife, toothbrush, and hairbrush and doing all kind of fasteners.

Scores on the PEDI also indicated that mobility was a domain of relative mastery for these children with DS. Parents did not report any situations of restricted participation stemming from disabilities in the mobility domain. However, the PEDI scores are based on functional outcomes, and do not take into account the quality of the performance. This distinction is particularly relevant in the mobility domain, where the mobility impairments of children with DS seem to be of a qualitative rather than a disabling nature (e.g., the parents report that the children need more time when climbing stairs and still use their arms to help themselves get in and out of chairs and on and off the toilet). Other gross motor assessment instruments may be more suitable and precise to describe these qualitative limitations.

Consistent with the literature, parents in this study reported language and communication to be of greatest concern. Peer interaction and play were reported as a specific concern by about 16% of the parents. The PEDI Functional Skills scores in the social function domain show considerable variation, and represent the lowest scores of the three domains (self-care, mobility, and social function). The mean Caregiver Assistance ratings are higher (indicating less need for assistance) in functional comprehension than the mean ratings for functional expression, which is also consistent with the literature (e.g., Berglund, Eriksson, & Johansson, 2001). Spiker (1990) has reported that problems in communication and in dealing with difficult behavior are the most consistent areas of concern in DS, highlighting continuing developmental problems with language and social skills. Parents in this study also reported challenging situations, such as children running away outdoors, related to developmental problems with language and social skills, and identified limitations in safety behavior as well. These issues raised concerns for the parents about the child’s ability to go to and from school safely and to participate with peers. Independent of the PEDI, some parents reported peer interaction and play to be a challenge. There are only a few items related to play skills and playfulness in the PEDI, thus further study is needed to describe the child’s skills in this area and identify potential targets for intervention. Other research (e.g., Sigman & Ruskin, 1999) has reported that play is a relative strength for children with DS, however level of skill is associated with current level of cognitive and communicative development.

An interesting result of this study was that the free reports (independent of the PEDI) from parents regarding areas of mastery and challenge for their child correlated well with the areas of concern identified on the assessment instrument. However, the open-ended interviews provided the caregiver’s own perspective on the relevance and meaning of these issues for their family. For example, many of the parents worried about not having a child who was toilet trained before starting school, and many related that they thought they were the only ones not succeeding in toilet training their child. Parents worried primarily about social stigmatization of their child by peers in school if this skill was not mastered. Existing Norwegian literature for parents suggests that most children with DS are toilet trained by the age of 4, which is not consistently supported by the research evidence (e.g., Carr, 1995). Further investigation of this issue would help address parental concerns by addressing questions such as: What characterizes the development of toileting control in children with DS? Is the sequence of development the same as for children without disabilities? Even if it becomes clear that development is particularly delayed in this area, this information will be important for parents who otherwise may feel that they have failed in this matter.
Limitations and Directions for Future Research

This study is cross-sectional, rather than longitudinal, and has a relatively small sample. Thus, the findings should be interpreted as providing general guidelines about typical function in 5-year-old children with DS, not firm standards for evaluating skill achievement. Replications with other samples, particularly samples from other countries, would increase confidence in conclusions regarding the typical level and range of daily activity performance in this population. The findings are also limited to the areas covered by the PEDI. Other important areas of occupation such as play are in need of further investigation. Finally, investigation of the relation between fine motor skills and independent performance of daily activities would be of great benefit to understand the sources of disability and guide efforts to improve performance in this area. The results of the present study suggest that support to master daily activities dependent on fine motor skills may be an important target area for occupational therapy intervention with this group of children.

Analysis of everyday function is often a starting point for occupational therapy assessment and intervention in children with DS, but there has been limited information with which to interpret assessment findings from a developmental perspective. This study contributes to our knowledge of functional performance in children with Down syndrome by providing evidence about the individual variability and areas of need for individual intervention. From the families’ perspective, disability situations were seen primarily in social function and self-care, and the greatest concerns were over social interaction, language, peer play, and participation in school without being stigmatized. These findings suggest areas of particular importance for practitioners to evaluate and discuss with families at the transition to elementary school.

Acknowledgments

The authors are grateful to all the parents who gave of their time and knowledge on behalf of their children, to senior lecturer Jo Kleiven, Lillehammer University College for statistical supervision, and the professional board of the Norwegian Network for Down Syndrome (NNDS) for support. The study was partially funded by Sykehuset Innlandet (SIHF), the Norwegian Occupational Therapy Association (NETF), and interview schemes from the Norwegian Psychological Association.

References


