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Fine motor and self-care milestones for individuals with Down syndrome using a Retrospective Chart Review

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Abstract

Background Developmental milestone markers for fine motor and self-care skills among children with Down syndrome (DS) are either minimal, anecdotal or out-of date. Our goal was to produce normative expectations for the development of fine motor and self-care milestones specific to children with DS.
Method A cross-sectional retrospective chart review was completed on 274 children with DS seen at a specialty clinic that ranged in age from 4 months to 18 years. Specific skills were assessed at occupational therapy assessments as either present or absent, including fine motor, handwriting, scissor usage, self-feeding and clothing management.
Results Fine motor milestones describing when 10–30% ('early achievers') and 75–95% ('representative achievement') of children with DS had mastered each skill were developed based upon descriptive review. As the fine motor and self-care skills advanced in complexity, the range of ages for documented skill acquisition was observed to increase.
Conclusions Age ranges for the mastery of fine motor developmental milestones for early and representative achievement were developed based upon descriptive analysis of cross-sectional retrospective clinical chart reviews. That the age range for mastering fine motor and self-care skills broadens as children with DS get older is in agreement with what is identified in the DS behavioural phenotype with regard to variable motor skills overall. These fine motor and self-care developmental milestone markers contribute to the field by informing parents, caregivers and healthcare providers of potential fine motor and self-care outcomes and describing normative development for children with DS.

Keywords Down syndrome, fine motor skills, milestones, self-care skills

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Down syndrome (DS) is the most common genetic cause of intellectual disability and occurs in 1 of every 691 live births (Parker *et al*. 2010). Individuals with DS most frequently have an extra 21st chromosome, which often causes motor, language and cognitive delays in addition to a variety of common physical features. A DS behavioural phenotype has been established to further explain behavioural outcomes associated with DS, including social–emotional functioning, cognitive development, motivation and motor functioning (Fidler 2005). The behavioural phenotype for children with DS

includes relative strengths in visual-spatial processing (Vicari *et al*. 1995; Jarrold *et al*. 1999; Vicari 2006) and social skills (Walz & Benson 2002), and relative deficits in verbal processing (Vicari *et al*. 1995; Jarrold *et al*. 1999; Vicari 2006) and some motor functioning (Vicari 2006) as well as self-care skills (Daunhauer & Fidler 2011).

Of importance in studying motor development and describing the behavioural phenotype in children with DS is whether there is a delay in achieving milestones. Basic motor skills are reported to be achieved by infants and children with DS in mostly the same order as their typical peers, but usually at significantly later ages (Cunningham & Sloper 1978; Winders 1997). In the 3rd edition of the Bayley Scales of Infant Development, 90 children with DS between the ages of 5 and 42 months were included in the reliability testing, supporting the use of the Bayley in measuring skills among children with DS (Bayley 2006). The children with DS performed well below the matched control group in the motor and language composites. The control group consisted of typically developing children who were matched based upon the demographics of the DS sample. They were not randomly selected, but selected based upon availability (Bayley 2006). The mean standardised motor score (*combined* gross and fine motor) in the DS population was 62.3 (SD = 11.0), substantially below the mean standardised motor score of 102.3 (SD = 14.6) in the typically developing matched control group. Similarly, the mean standardised language score was 70.8 (SD = 10.6) in the DS population and 103.7 (SD = 14.2) in the control group.

In addition to delayed language and motor milestones among children with DS, there is evidence of greater variability in the development of gross motor skills when compared with same age children who are typically developing (Winders 1997). For example, the average age for walking in typically developing children is 13 months and the range is 9–17 months, while the average age for walking in children with DS is 24 months and the range is 14–42 months (Cunningham & Sloper 1978; Winders 1997). While a broad range of skill acquisition may be encouraging for parents, it is important for professionals to understand that the range is likely negatively skewed. For instance, there are likely many children with DS who are not achieving these skills in the early range, which may impact how the range is interpreted. Therefore, it is important to know what proportions of children are attaining the skills during different age ranges. For gross motor skills, developmental milestones exist and would benefit from additional specificity. For fine motor and self-care milestones, both areas warrant development.

Despite this attention to the development of language and gross motor skills, there is a lack of research on fine motor and self-care development for individuals with DS. There are presently milestone checklists for individuals with DS for expressive and receptive language (Roberts *et al*. 2007) as well as for gross motor skills (Winders 1997). However, a milestone checklist for fine motor and self-care skills is currently lacking, as well as descriptions of these skills in relation to the DS behavioural phenotype (Fidler 2005; Daunhauer & Fidler 2011).

The most recent published information on fine motor milestones lists only four motor skills and was published over 30 years ago; these skills included grasping a cube (4–10 months), passing an object from one hand to the other (6–12 months), putting three or more objects into a cup (12–34 months) and building a tower of two 1-in. cubes (14–32 months) (Cunningham & Sloper 1978). While these data provide important information, they are limited by the small number of skills assessed and are in need of expansion and updating to help guide clinical practice and parental expectations. More recently, Bruni (2006) has provided guidelines related to fine motor development, which are based upon personal experience, for children with DS between birth and 2 years of age, 2 and 4 years of age, 5 and 8 years of age, 9 and 12 years of age, and 13 years and older.

While these guidelines are helpful, there is an ongoing need for empirically derived fine motor and self-care milestone data based upon the current population of children with DS. New and empirically derived fine motor and self-care milestones will improve healthcare providers' ability to provide parents with realistic expectations on their child's development and likely improve service planning. Fidler *et al*. (2002) found that parents of children with DS reported their child's occupational therapist is not often able to provide aetiology-specific

information to the team for use in intervention planning. Such guidelines would allow providers to identify when fine motor and self-care delays may exceed those typically anticipated in the DS population and serve to prompt evaluations for co-morbid problems, such as sensory processing deficits or medical conditions limiting performance. Guidelines would also be important to parents by providing a better understanding of occupational therapy and fine motor skill development and expectations, and that fine motor skills contribute to gains in independence in their daily lives including self-care, play, school, work and community management.

The purpose of this study was to develop fine motor and self-care milestone markers for children with DS using data from a retrospective clinical chart review. In selecting fine motor skills to monitor for milestone development, we made an effort to include skills we believe to be of importance in the classroom, to parents and to occupational therapists. This information is essential and clinically relevant as it will provide professionals with fine motor and self-care milestones to monitor development of children with DS. It will also supplement the research on the DS behavioural phenotype.

Method

Selection and recruitment of participants

A retrospective chart review was conducted on children with DS seen for occupational therapy evaluations at an outpatient multidisciplinary DS clinic at a Midwestern children's hospital from 2005 to 2010. Children were referred to the clinic on the basis of their diagnosis of DS for specialty evaluations and paediatric guidance. Individuals in the sample were primarily (83.7%) seen on a consultative basis by the multidisciplinary outpatient team (developmental behavioural paediatrician, social work, speech-language pathology, nutrition, special education, physical and occupational therapy) on one day. The remaining children were seen in the specialty clinic by a paediatrician first and then referred for allied health evaluations on different appointment days as part of routine clinic practice (15.3%). The clinical model was that all children referred to the clinic received updated allied health evaluations. The teams evaluated children birth up to 3 years of age collectively and performed consecutive individual assessments for children ages 3 and older. Patients at the clinic primarily are from the surrounding area where the hospital is located; however, the clinic does see patients from across the United States. Children referred to the specialty DS clinic match the race and gender distribution of children referred to the greater children's hospital. Occupational therapy assessments were made to evaluate current developmental status.

Individuals with a secondary diagnosis of autism or another condition were not excluded from the retrospective chart review. Frequency estimates of other conditions at the greater children's hospital mirror those reported in the general literature. For example, 2.7% of children seen at the great hospital were dually diagnosed with autism and DS, while prevalence estimates ranged from 1% to 7% (Kielinen *et al.* 2004; DiGuiseppi *et al.* 2010; Bull 2011). Consent for retrospective chart review was obtained from the Institutional Review Board of the academic medical center.

Three hundred and fifty individuals met these criteria and ranged in age from 1 month to 18 years of age initially. Children under the age of 4 months, who had yet to meet any of the milestones, were excluded from the analyses. This resulted in a sample size of 274 children with a mean age of 65 months (SD = 57 months; Mdn = 50 months). One-third of the participants were less than 24 months of age and the top one-third of the participants were older than 72 months of age. Fifty-six per cent were male. The sample was 83.8% Caucasian, 7.5% African-American, 0.6% Asian and 8.1% identified their race as 'other'. Just over 5% of the sample identified as Hispanic. One hundred and seventy-two of the 274 participants had established hand dominance. Of these individuals, 73% were right hand dominant.

Measures

Two tools were utilised to collect the data; these include the Bayley-3 in addition to clinical observations of the first author. Parental report supplemented clinical observations during the routine occupational therapy assessment. Ten fine motor skills were assessed using the Bayley-3 (Bayley

Table 1 Items measured on the Bayley-3

Skill	Item number on Bayley-3
Fine Motor	
(a) Transfer an object from one hand to the other	21
(b) Use a raking grasp when picking up small items	17
(c) Intentionally drop and release an object into an open container	33
(d) Utilise a pincer grasp with either their index or middle fingers	26
(e) String three average cube size beads onto a shoe string	45
Handwriting	
(a) Hold a regular crayon (not fat or triangular) and mark on the paper	30
(b) Trace pre-writing shapes (–, l, 0)	40, 41, 43
Scissor	
(a) Snip paper	47
(b) Cutting a 4-inch-long line that was approximately 1/8 inch wide	55
(e) Cut a 3-inch-diameter circle with 1/8-inch-wide lines with no straight edges	64

2006) and displayed in Table 1. The Bayley-3 is a comprehensive assessment tool that measures cognitive, language and motor skills in children ages 1–42 months. The Bayley-3 has established psychometric norms for special populations, including children with DS. The Bayley-3 is the standard tool used in the DS specialty clinic because of the availability of developmental norms appropriate for individuals with DS. The Motor Scale fine motor subtest items from the Bayley-3 were used to assess fine motor, handwriting and scissor skills of children with DS ages 4–42 months.

An additional 18 fine motor and self-care skills were assessed by clinical observation of behaviour in the clinical setting, following standard practice in the specialty clinic. Additional writing and scissor skills selected for measurement are typical skills required in a classroom setting and are often the focus of occupational therapy intervention in the educational setting. They are also skills measured in developmental motor assessments such as the Peabody Developmental Motor Skills – 2nd edition (PDMS-2), an assessment tool that is commonly used to assess motor skills in children from birth through 5 years of age (Folio & Fewell 2000) and the Bayley-3 (Bayley 2006). The skills assessed under self-feeding and clothing management were selected as parents often question when achievement will occur for these specific skills.

The age of the child at the time of the occupational therapy visit when they demonstrated mastery of the skill is reported in months. The following skills were documented in the chart review.

Fine motor

Ability to (a) transfer an object from one hand to the other; (b) use a raking grasp when picking up small items; (c) intentionally drop and release an object into an open container; (d) utilise a pincer grasp with either their index or middle fingers; and (e) string three average cube size beads onto a shoe string. All of the fine motor skills were measured using the Bayley-3.

Handwriting

Ability to (a) hold a regular crayon (not fat or triangular) and mark on the paper; (b) trace pre-writing shapes (l, –, o); (c) trace the letters of their name; (d) copy a sequence of letters (name); (e) copy a sequence of numbers correctly; and (f) independently write their name legibly without regard for spacing and alignment. Skills 'a' and 'b' were assessed using the Bayley-3. Skills 'c', 'd', 'e' and 'f' were assessed by clinical observation.

Scissor skills

Ability to (a) snip paper using regular scissors while holding them with thumb up and holding the 8½ × 11 inch paper with the non-dominant hand. These same techniques were measured while (b, c, d) cutting a 4-, 8- and 11-inch-long line that was approximately 1/8 inch wide. There must not have been any deviations from the line in order to be recorded. Finally, we documented their ability to (e) cut a 3-inch-diameter circle with 1/8-inch-wide lines with no straight edges. Scissor skills 'a', 'b' and 'e' were measured using the Bayley-3. Skills 'c' and 'd' were assessed by clinical observation.

Self-feeding skills

The ability to (a) independently hold a bottle (regardless of size and shape); (b) self-feed finger foods; (c) independently scoop with a spoon and (d) spear with a fork; (e) drink from an open cup independently; and (f) drink from a straw independently. The self-feeding skills were assessed using clinical observation and supplemented with parental report.

Clothing management skills

The ability to (a) get dressed/undressed independently excluding fasteners (clothes on correctly and shoes on correct feet); (b) independently zip/unzip; (c) independently fasten button on pants; (d) independently fasten buttons on a shirt; (e) tie their shoes; and (f) when they were toilet trained. The clothing management skills were measured using clinical observation and supplemented with parental report.

Data collection

Data were collected on 274 children from a total of 361 visits. Children seen for multiple assessments (49 seen twice, 14 seen three times, 2 seen four times, 1 seen five times) primarily had returned to the consultative outpatient clinic for reassessment several years later. For example, the child was seen as a toddler and returned for reassessment of fine motor skills during kindergarten. Some children were reassessed as follow-up evaluation post standard therapy. The children seen for multiple visits exhibit data points that do not appear to be outliers and appear consistent with the developmental profile of the other children in the sample.

A de-identified cross-sectional database was retrospectively created including the following variables that were obtained through parent/caregiver report, specific items from the Bayley-3, and/or therapist observations at occupational therapy visits: age at time of visit (in months), gender, race, ethnicity, hand dominance, and yes/no determinations if the skills were achieved for five fine motor skills, progression of handwriting skills, five scissor skills, six self-feeding skills and six clothing management skills.

As standard clinical care did not assess all skill domains for all ages of children, not all skills were available to be documented as present or absent for each participant. For instance, a 5-year old may have been seen for an evaluation, but because of age and current skill level, raking grasp (a skill that develops earlier) was not assessed at that evaluation and entered into the chart as it was presumed to be present. Also, because of the retrospective nature of the study and the individualised assessments conducted in clinic, some data were unknown at the time of the visit and therefore omitted from the current study. For each of the 274 individuals in the study, data were not available for each skill. Only the skills that could be assessed on the date of their visit and available for review are included. Table 2 lists the number of individuals for whom data were assessed for each skill area. The fine motor and scissor skills milestone ranges for typically developing children were taken from three sources in order to match the skills measured among children with DS (Calder 2007; Glascoe & Robertshaw 2007; Gerber *et al*. 2010). As different fine motor skills are tracked for typically developing children in the children's hospital, a comparison group could not be extracted with a retrospective chart review. The developmental milestone age expectation for typically developing children from the three sources is used for illustrative purposes and general comparisons. Statistical comparisons are not made.

Data analysis

The data were descriptively analysed. As data reflected whether a skill was present at a specific age and not the age of attainment of each skill, mean ages of skill attainment are inappropriate to report. Instead, the proportion of children at a particular age range who had attained each skill was calculated. To capitalise on the larger sample size at younger ages and because of the variety of fine motor skills assessed that develop at younger ages, the proportions were calculated for 2-month age intervals up to the age of 24 months, for 3-month intervals between 24 and 60 months, for 6-month intervals for children age 5–8 years and for 24-month intervals for children older than 8 years. These intervals ensured proportional numbers of observations for each age range (see Table 3).

Table 2 Fine motor and self-care milestones for individuals with Down syndrome

			Peers with Down syndrome		
Motor milestone	**Typical peers†**	**Number of observations**	**Early (10–30%)**	**Representative (75–95%)**	**Number of outliers**
Fine motor					
Raking grasp	6–7 months	148	5–8 months	9–12 months	1
Transfers	5–7 months	144	7–8 months	12–18 months	0
Pincer grasp	10–12 months	173	13–16 months	22–66 months	8
Intentional drop/release	13–15 months	178	11–14 months	22–36 months	3
String beads	28–36 months	143	43–59 months	72–144 months	1
Handwriting					
Hold crayon and scribble	12–16 months	208	9–12 months	22–36 months	6
Traces pre-writing shapes	22–36 months	226	31–45 months	60–120 months	7
Traces letters in name	36–48 months	223	40–66 months	108–144 months	5
Copies a sequence of letters	48–50 months	223	52–72 months	120–144 months	7
Writes name independently	60–72 months	226	67–96 months	120–216 months	0
Copies a sequence of numbers	60–72 months	212	58–96 months	168–216 months	0
Scissor					
Snipping paper	23–29 months	200	37–57 months	60–96 months	6
Cutting 4" straight line	30–35 month	202	61–66 months	84–144 months	4
Cutting 8" straight line	36–41 months	198	61–78 months	120–216 months	0
Cutting 11" straight line	42–48 months	195	61–96 months	120–216 months	0
Cutting curved line	48–57 months	199	79–90 months	180–216 months	0
Self-feeding					
Hold bottle independently	6–8 months	119	5–8 months	16–27 months	6
Self-feed with fingers	8–12 months	261	9–10 months	20–22 months	10
Feeds with spoon	15–20 months	258	28–33 months	42–72 months	7
Drinks from straw cup	20–24 months	171	13–27 months	36–60 months	4
Drinks from open cup	22–36 months	166	28–42 months	66–90 months	5
Feeds with fork	36–48 months	250	28–57 months	66–90 months	4
Clothing management					
Toilet trained	33–48 months	246	39–66 months	90–168 months	0
Dress/Undress no fasteners	36–48 months	244	49–66 months	168–192 months	1
Independent zipper	48–60 months	235	79–96 months	216 months	0
Independent button on pants	42–52 months	237	109–168 months	216 months	0
Independent button on shirt	48–54 months	235	169–192 months	216 months	0
Tie shoes	60–72 months	236	121–192 months	216 months	0

† Developmental milestone age estimates for typical peers extracted from Calder (2007), Gerber *et al.* (2010) and Glascoe & Robertshaw (2007).

The proportion of children at each age range who had attained each skill was calculated and graphed for visual inspection. For the purposes of our manuscript, we defined 'early achievement' as when 10–30% of the children with DS assessed at a particular age had mastered the skill. For example, if 15% of 5–6 month olds, 25% of 7–8 month olds, 20% of 9–10 month olds and 50% of 11–12 months olds demonstrated a particular skill, we defined the 'early achievement' as 5–10 months. We defined 'representative achievement' as when 75–95% of children with DS assessed at a particular age had mastered the skill. As some children struggle with attaining fine motor and self-care milestones, we included the number of outliers who had not attained each milestone within the ranges visually identified. These outliers represent less than 5% of the children sampled on each skill. Each child masters skills at different points in their development. For this reason, we found it important to

Table 3 Number of observations in each age span

Age span	Total observations
2-month intervals	
5–6 months	8
7–8 months	12
9–10 months	18
11–12 months	14
13–14 months	19
15–16 months	7
17–18 months	9
19–20 months	10
21–22 months	4
23–24 months	7
3-month intervals	
25–27 months	4
28–30 months	10
31–33 months	13
34–36 months	11
37–39 months	6
40–42 months	10
43–45 months	5
46–48 months	10
49–51 months	7
52–54 months	4
55–57 months	12
58–60 months	8
6-month intervals	
61–66 months	16
67–72 months	12
73–78 months	11
79–84 months	11
85–90 months	11
91–96 months	11
24-month intervals	
8–9 years	22
10–11 years	18
12–13 years	12
14–15 years	10
16–17 years	11

state the range of when skills began to be mastered by a few as well as when the majority mastered them.

Results

Among the children sampled at each age range on their ability to perform a raking grasp, 10–30% of 5- to 8-month-old children were able to perform this skill (see Fig. 1). By 9–12 months of age, 75–95% of children in this age range were demonstrating this skill. In comparison, typically developing children are documented to attain this skill around 6–7 months of age (Glascoe & Robertshaw 2007). Detailed results for the remaining fine motor and self-care milestones are presented in Table 2 along with the number of outliers.

When looking at the fine motor skills and writing skills, the early achievers with DS appear to master the skills around the same age as their peers; however, as the skills become more difficult, the difference in the ages of mastery between children with and without DS appears to increase. All of the self-feeding skills, with the exception of spoon-feeding, begin to emerge around the same ages as typical peers for some children with DS. Toilet training may begin to emerge around the same age as typical peers, but the age range of mastery for children with DS is much greater. All children with DS appear to master scissor skills and clothing management skills at later ages than their typical peers.

Discussion

Fine motor and self-care milestone markers for children with DS were generated based upon a descriptive analysis from a retrospective review of clinical charts. Our fine motor milestone markers support and extend previous data and recommendations for skill development in children with DS. The retrospective chart review included two of four fine motor skills measured by Cunningham & Sloper (1978). The currently developed milestone markers were consistent with previous milestone markers, which identified that transferring occurs between the ages of 6 and 12 months in individuals with DS and intentional drop and release occurs between the ages of 12 and 34 months. Our findings extend the current literature by expanding the range of skills assessed for evidence-based milestone markers.

Our milestone estimates for skill development are relatively consistent with those recommended by Bruni (2006) of when skills should develop. For the progression of handwriting skills, the age ranges found in our study are larger than what Bruni suggested. For the early handwriting skills, our early achievers mastered the skill in the same age range as

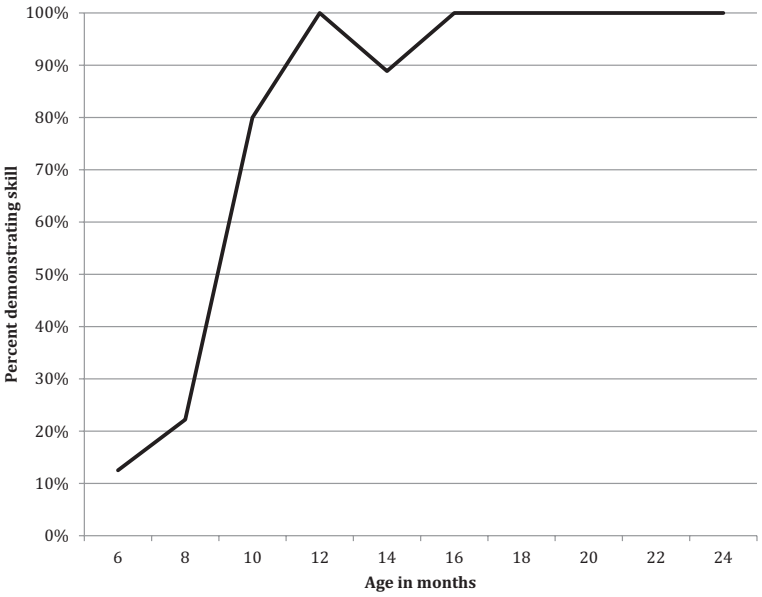

Figure 1 Percentage of children demonstrating raking grasp for various age intervals.

Bruni suggested; however, our representative group (75–95% of the sample) mastered the skill much later. For the later handwriting skills, Bruni suggested that age range falls somewhere between our early achievers and representative group. However, for the scissor skills, Bruni suggested that age of skill development is often younger than what was observed in our study. Our results found early achievers master self-feeding skills consistent with Bruni's recommendations, but the majority of our sample mastered the skill of feeding with a spoon later than her suggested 24–48 months of age range for development. In each of the clothing management skills, our range of development is larger than what Bruni suggested and representative mastering of the skill began later in our sample. Bruni did not comment on developing the skill of toilet hygiene, which we observed to be completed for some between 3 and 5 years of age, and for others between 7 and 13 years of age. Overall, our milestone markers for fine motor and self-care skill development are consistent with those anecdotally reported by Bruni. We expand upon her work by using data from a structured clinical chart review, a more detailed range of skill development, and identifying skill development in early achievers and the representative group.

Consistent with previous assessments of these fine motor skills, it appears that children with DS achieved these skills at later ages than observed in the general population (Winders 1997; Bruni 2006; Daunhauer & Fidler 2011). Our examination of fine motor developmental milestones suggests that skill development in children with DS is heterogeneous and occurs over a broad age range. To support children with DS being a heterogeneous group in terms of fine motor development, the range of when skills are either achieved early or as a representative group was observed to get wider as the skills got more complex. This finding suggests that skill differences diverge among children with DS as the children get older and as the skills get more challenging, which supports previous findings of skill development slowing with age (Dykens *et al.* 2000; Fidler *et al.* 2009). As small discrepancies in development at young ages can aggregate into a more pronounced deficit, this finding emphasises the importance of early intervention. As part of best practice clinical care, introducing skills at developmentally appropriate ages is important. Our findings provide clinicians a normative age range to guide practice and when to introduce skills.

Our findings also suggest that individual achievement will vary from child to child. Our data support

what Fidler *et al*. (2009) suggested that by understanding the behavioural phenotype, it can guide educational planning, help practitioners identify deficit areas and help families be more proactive in the treatment of their child with DS. Also, establishment of fine motor and self-care milestones makes it possible for practitioners to identify targets for intervention, appropriate timing for the intervention, and specialise the intervention for individuals with DS (Fidler *et al*. 2009).

Based upon the behavioural phenotype, it is well understood that each child with DS will achieve developmental milestones with great variability (Daunhauer & Fidler 2011). For instance, one child with DS may have superior gross motor skills compared to their communication and fine motor skills just as another may have superior communication skills compared to fine and gross motor skills. This concept also applies to the development of fine motor and self-care skills. A child may be able to feed themselves with a spoon, but have difficulty with early handwriting skills. When a child is achieving some milestones in the early achiever range, it remains a possibility they will achieve other milestones in the representative range. Therefore, there is variability in the rate of skills acquisition over time. We have identified the number of study participants who did not fall within the early achiever or representative age ranges as outliers in Table 2. Even though one child with DS is mastering skills earlier than other children with DS, occupational therapy may still be warranted to foster ongoing skill development and support development in other domains such as academics.

While children with DS master skills at various ages, Bruni (2006) suggested a similar pattern of development of fine motor skills for each individual. These are the foundational skills, which include stability, coordination and sensation. Once these skills are mastered, dexterity begins to develop, which leads to the mastering of daily living skills. The developmental sequence of mastering skills observed in this study is consistent with Bruni's suggestion. Our findings demonstrate the need for the foundational skills first before more refined skills can be developed. For instance, a child needs to have, at minimum, a raking grasp (early achievers 5–8 months) before being able to self-feed finger foods (early achievers 9–12 months), and the ability to use both hands together such as in stringing beads (early achievers 43–59 months) before being able to manipulate fasteners on clothing (early achievers 49–66 months). Therefore, certain basic skill development is necessary in order to master more refined skills.

There are significant clinical implications of these findings for both parents and clinical providers. The milestone markers provide parents with a better understanding of normative development for fine motor and self-care skills for their child with DS as well as clearer expectations for their child's potential development. The milestones provide professionals with guidelines to structure when to introduce new skills into therapy, information to share with parents within therapeutic goal setting, and a better understanding of the range of development among children with DS, including development within the typical range. Our findings also provide a basis for expanding the description of the DS behavioural phenotype by demonstrating specific fine motor and self-care milestones as well as providing further data to support the development of motor skills.

Despite the significant contribution of our fine motor milestones, there are some limitations that should be identified to understand how the milestone should be interpreted. Firstly, our sample was generated from a clinical sample previously seen at one DS specialty clinic. Therefore, the sample may limit generalizability to all children with DS not seen in a specialised clinic. However, the children referred for occupational therapy evaluations were not children who had specific fine motor concerns, and the sample was also representative of the demographics of children seen across the hospital as a whole. As a result, we feel confident that the children seen for evaluation include a broad range of children with DS. Secondly, the data were collected from the date the child was seen and not the date the milestone was presumed to have developed. Therefore, the skill could have been achieved prior to the clinic visit. In this case, our milestones would be conservative estimates of when the skills were achieved. Thirdly, some of the fine motor skills assessed are no longer daily tasks for individuals and may impact findings. For example, oftentimes individuals with DS wear elastic waist band pants, overhead shirts and slip-on shoes to avoid the frus-

tration of manipulating buttons and other fasteners. Fourthly, the skills were selected for retrospective chart review based upon the function they perform rather than occupational therapy goals. For instance, it may have been possible to analyse all fine motor grasps, but parents have less interest in whether or not their child is using a pincer grasp vs. a power grasp as long as the child is able to use their hands in a functional manner. Further, some of the skills are stepping stones to tasks parents are interested in such as tracing pre-writing shapes, which eventually leads to independently writing one's name. And lastly, only one occupational therapist performed all assessments, and data were gleaned from chart reviews, limiting the ability to determine reliability of the assessments between different therapists, or to determine the reliability of information obtained from the Bayley vs. clinical observation. Despite these limitations, the occupational therapist performing assessments specialised in working with children when DS, a considerable asset in accurately assessing these fine motor skills.

This study contributes to our understanding of the development of fine motor and self-care skills for children with DS. Fine motor and self-care skills of individuals with DS from infancy to young adulthood were examined through a retrospective chart review to produce expected age ranges for the development of fine motor and self-care milestones. These results provide the needed guidelines for when fine motor and self-care skills are achieved in the DS population and guide clinical practice and parental expectations. Future research is needed to validate the fine motor and self-care milestones established and compare these data to other children with similar developmental ages instead of chronological age. Also, a longitudinal study where children with DS could be followed up as development occurs would further fine-tune the fine motor and self-care milestones.

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