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ORIGINAL ARTICLE

Parents' perceptions of functional abilities in people with Down syndrome

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Abstract

A realistic assessment of the range of functional abilities found in people with Down syndrome (DS) may assist in counseling expectant parents. This study asked parents from the United States and the Netherlands to assess 11 functional skills of their sons and daughters with DS: walking, eating, speaking, grooming/personal hygiene, reading, writing, preparing meals, working at a job, going on dates, traveling independently, and living independently. We analyzed responses from 2,658 parents who have sons/daughters with DS of all ages. The majority of people with DS in the United States could walk by 25 months of age, speak reasonably well by 12 years, maintain their own personal hygiene by 13 years, and work independently by 20 years. By 31 years of age, 49% were reading reasonably well, and 46% were writing reasonably well. Approximately 30% could travel independently, and 34% were living independently. The results from parents in the Netherlands were similar for most measures. This normative data on function may contribute to anticipatory guidance and decision-making. Furthermore, as parents and clinicians seek to assess the relative strengths and weakness of people with DS, resources and supports can be marshaled for those not meeting milestones at expected times.

KEYWORDS

development, Down syndrome, occupational therapy, physical therapy, speech and language pathology, trisomy 21

1 | INTRODUCTION

Approximately 206,000 people in the United States, as of 2010, have Down syndrome (DS) (de Graaf, Buckley, & Skotko, 2016a), with about 5,000 babies with DS born annually in recent years (de Graaf, Buckley, & Skotko, 2015a). Increased access to noninvasive prenatal testing, however, means more expectant couples are receiving a prenatal diagnosis of DS (de Graaf et al., 2015a). The American College of Medicine Genetics and Genomics recommends that couples be provided "accurate, balanced, up-to-date information, at an appropriate literacy level...in an effort to educate prospective parents about the condition of concern. These materials should reflect the medical and psychosocial implications of the diagnosis" (Gregg et al., 2016). For post-test counseling, the National Society of Genetic Counselors recommends that clinicians "provide a range of possible outcomes to

illustrate what life is like for individuals with DS and their families" (Sheets et al., 2011). This charge can be challenging for many physicians since robust studies are not available to address the pressing questions asked by many parents about real-life expectations: When would a child with DS be expected to walk? Can we expect them to speak understandably? Work at a job? Live independently?

Previous research has documented that expectant couples often feel that they receive incomplete and inaccurate information during prenatal counseling (Sheets et al., 2011; Skotko, 2005; Skotko et al., 2009). Yet, scant research has assessed the functional skills attained by people with DS. Children with DS have an average onset of meaningful speech at 21 months, according to one longitudinal laboratory-based study (Smith, 1984). About 44% of parents who had teenagers in the Netherlands felt their child's speech was understood by most other people (Van Gameren-Oosterom et al., 2013). In Rome, Italy, 52% of parents felt that their sons/daughters with DS, ages 14–62, had little to no difficulty in being understood (Bertoli et al., 2011), and

Abbreviation: DS, Down syndrome.

in a recent U.S. study, 45% of parents felt their adults with DS had no difficulty in using verbal communication (Matthews et al., 2018).

Gross motor and fine motor skills in children with DS are also delayed in comparison to neurotypically developing peers. In a study of 133 children with DS, ages 1 month to 6 years and enrolled in Early Intervention programs in Canada, therapists assessed motor development with a validated tool. More likely than not, children with DS were found to be rolling by 6 months, sitting by 12 months, crawling by 24 months, standing by 24 month, walking by 2 years and 6 months, jumping forward by 5 years, and running by 6 years (Palisano et al., 2001). Clinicians in Chicago, IL, did a retrospective review of fine motor assessments from a DS specialty clinic of 274 patients with DS, ages 1 month to 18 years (Frank & Esbensen, 2015). At least 75% of people with DS could self-feed with fingers by 20–22 months of age, hold a crayon and scribble by 22–36 months, demonstrate a pincer grasp by ~2–5.5 years of age, feed with a fork by 5.5–7.5 years, and write their name independently by 10–18 years.

Some self-help skills have been assessed using clinical observations and parental report (Frank & Esbensen, 2015). At least 75% of people with DS in the United States were toilet trained by 7.5–14 years of age and could dress/undress themselves without fasteners by 14–16 years. By 18 years, at least 75% of people with DS could independently use a zipper, button, and tie their own shoes (Frank & Esbensen, 2015). In a large population-based study in Rome, Italy, the majority of people with DS were able to wash themselves by age 14–19 years and go out alone by age 25–30. By age 25–30, about 44% had little to no difficulty preparing simple meals, and 46% had little to no difficulty using public transportation. More likely than not, people with DS could write and read easily by age 20–24. Approximately 31% of adults with DS, ages 25–30, were working often, including in sheltered work places. By contrast, in the Netherlands, about 40% of teenagers, ages 16.8–19.9 years, could tie their own shoes; 60% were able to dress themselves; 6% could perform basic cooking; and 6% use public transportation independently to a familiar place (Van Gameren-Oosterom et al., 2013). About 42% of these teenagers could read and understand short texts in books and magazines, and, overall, up to 60% of teenagers had mastered some of the skills required for independent living.

The purpose of this research is to provide normative data about functional skills of greatest importance to families. While direct measurements by healthcare professionals might be more clinically valid, we purposely aimed for ecologic validity, especially since many of the milestones of interest lack standardized clinical assessment tools. We measured day-to-day functioning of people with DS as perceived by family members. Here, we present the results from more than 2,600 families between two countries, asking about the functional abilities of people with DS through childhood, adolescence, and adulthood.

2 | MATERIALS AND METHODS

2.1 | Participants

In the United States, a survey was mailed to 4,924 family members of six nonprofit DS organizations, chosen for their size, cultural compositions, and geographic distribution (Skotko, Levine, & Goldstein,

2011a). These included the Down Syndrome Association of Atlanta (757 members), Massachusetts Down Syndrome Congress (1,143 members), Mile High Down Syndrome Association (Denver, CO) (877 members), Triangle Down Syndrome Network (Raleigh, NC) (280 members), Down Syndrome Association of Central Texas (371 members), and Down Syndrome Association of Los Angeles (1,574 members). The research was originally approved as protocol H-26552 by the Institutional Review Board of Boston University Medical Center, where some of the authors were based at the time the surveys were conducted. This research was exempted from review for secondary data analyses from Partners Human Research Committee.

In the Netherlands, parents were recruited through the e-newsletter, magazine, Facebook page, and website of the Dutch Down Syndrome Foundation (SDS) and invited to complete an online questionnaire. SDS was founded in 1988 and is a nonprofit DS organization with approximately 3,300 members of which 2,100 families had a child with DS, as of 2016. Of these, there were 353 families who had a child with DS, ages 0 up to 5, which represents about 36% of the total number of families who have a child with DS in this age range in all of the Netherlands. There were 779 families with a child with DS, ages 5 up to 13 years (~42% of all families with a child with DS in this age range in the Netherlands), 586 persons with DS, ages 13 up to 21 (~30%), and 404 persons with DS, ages 21 and older (~5%). The SDS e-newsletter is read by families and professionals and by members and nonmembers of the SDS. Of the around 4,000 readers, an estimated 80% (3,200) are families that have a son/daughter with DS, of which around 1,100 are nonmembers of the SDS.

2.2 | Survey instrument

The survey instrument in the U.S. study has been previously described in detail (Skotko et al., 2011a, 2016) and is available as Supporting Information. As part of larger content, parents were asked about the current functional abilities of their child according to Likert statements on a scale of 1–7 with "7" indicating "very well," "4" indicating "somewhat/sometimes," and "1" indicating "not at all." The 11 functional abilities assessed included walking, eating, speaking, grooming/personal hygiene, reading, writing, preparing meals, working at a job, going on dates, traveling independently, and living independently. Caregivers were also asked two other questions: "To what extent does your son or daughter with Down syndrome, in your opinion, have significant health problems?" and "To what extent does your son or daughter with Down syndrome, in your opinion, have significant educational/learning difficulties?" For each, they were asked to respond on a 7-point Likert scale with "7" indicating "very much a problem," "4" indicating "somewhat a problem," and "1" indicating "not a problem." These surveys were completed between October 4, 2008, and January 31, 2009. The survey was also translated into Spanish, and the Spanish version was mailed to known Spanish-speaking families.

In the Netherlands, the same questionnaire was used. Two members of the SDS who were parents from a bilingual family with a child with DS performed the translation. However, in some circumstances, precise translations were unavailable. The category "4" ("somewhat/sometimes") was translated to the Dutch word "redelijk," which, in retrospect, is more

similar to "reasonably well" than to "somewhat/sometimes." Category "3" was translated to the Dutch word "matig," which means "not too well," and probably is more akin to "somewhat/sometimes." The translation of the Likert scales for health problems and educational challenges was more literal. In the Netherlands, the questionnaires were completed between March 24, 2016, and July 5, 2016.

In both studies, sociodemographic background variables were collected.

2.3 | Data analyses

For both the U.S. and Dutch participants, summary statistics were calculated for each of the parent-reported functional abilities. We also report the percentages of respondents who reported their son/daughter had achieved a functional ability at least reasonably well (defined as ≥5 on the Likert scale in the United States and ≥4 in the Netherlands), with comparisons made between countries.

In contrast to the Dutch survey in which age of the person with DS was measured in whole years, in the U.S. survey, age of the person with DS was measured as the difference between the day of survey completion and the day of birth of the person with DS. This more precise measurement enables an estimation of percentile values for the different skills. Put another way, we were able to estimate at which age, in months, 10%, 25%, 50%, 75%, and 90% of the people with DS can perform each skill at least reasonably well. This is estimated by constructing overlapping age groups with a width of 11 months, plotting the percentage of persons scoring at least reasonably well for a certain age group against the midpoint of this age group (e.g., 0–10 months has a midpoint of 5 months), and subsequently finding the best fitting regression line for the period in which there is development of this skill.

For further analysis, a composite functional activity score was calculated for each child by summing the 7-point Likert statements of each of the 11 functional activities. Any response of "not applicable" was assigned a score of "1," with the composite functional activity score ranging between 11 and 77.

Since we were interested in explaining the variance in development—that is, the extent to which a person has acquired functional abilities in comparison with same aged peers with DS—we constructed a variable that captured this relative position. As the relation between total functional score and age is not linear, dividing the total functional score by age does not help. This leads to a variable with a strong negative correlation with age and not to an age-independent position value.

Consequently, we explored other possibilities. The relationship between total functional score and age revealed that above 30 years, there was no significant increase in functional abilities—that is, the t test of the total functional score for those aged 20–30 versus those aged 30 years and older is not significant in both the U.S. and Dutch cohorts. We next assigned the age of 30 to every person of 30 years of age and above, and we subsequently explored the relation between age and total functional score for people of all ages. For both the U.S. and Dutch cohorts, cubic functions best predicted this relation (R^2 = 0.634 for the United States and R^2 = 0.583 for the Netherlands). The cubic regression lines resembled almost perfectly the interpolation lines that are drawn by using the nonparametric SPSS locally

weighted scatterplot smoothing function, which is a method used if one does not know what global relation should be assumed between two variables and builds the function point-by-point on basis of subsets of the data. As a result, on the basis of these cubic regressions, we were able to predict the total functional score that someone would be expected to have based on his or her age for both cohorts. By dividing the real functional score of each person by their age-related expected functional score, multiplied by 100 for readability, we constructed a variable which has no correlation at all with calendar age (Pearson correlation <0.02 in both cohorts). This variable can be seen as a measure for how well someone with DS is developing, as perceived by their parents, in comparison with same aged peers with DS. We named this variable "developmental quotient of functional abilities" or, for short, "dq-functional." By constructing this variable for both cohorts separately, we have also addressed the fact that the raw scales are not fully identical, as dq-functional is a measure of the position of the person in relation to same-aged peers from their own country. A higher dq-functional score implies relatively well-developed functional abilities, as perceived by parents.

For both cohorts with the parent-reported health-conditions scale and the educational-challenges scale, parents tended to report higher scores (i.e., reported more problems) as the person with DS got older. To construct a score that best represented the person with DS's relative health problems and educational challenges as compared to same aged peers with DS, we followed the same procedure as described above in relation to functional abilities, for both cohorts separately. The newly constructed variables are named "position-health" and "position-educational" or, for short, "pos-health" and "pos-educational." As a higher raw score implies more problems or challenges, a higher pos-health and/or pos-educational scores do as well.

To investigate which variables might best predict the dq-functional, we performed mixed stepwise, multivariate regression analyses, using pos-health, pos-educational, child's biological sex, and sociodemographic background variables as predictors (Table 1). To determine significance of our models, ANOVA was performed and R^2, df, F, standardized Beta coefficients, and p-values for the models and predictors that achieved significance at .05 level are reported.

3 | RESULTS

3.1 | Respondents

3.1.1 | U.S. cohort

As previously reported, of the 4,924 families invited to participate, Skotko et al. (2011a) received 2,044 responses from parents and guardians, which represents 1,407 surveys from at least one parent or guardian in each household, a 29% response rate. Of the 2,044 responses, 54 declined to respond, and one was from a person living outside of the US, leaving 1,989 surveys for inclusion in our analyses. For Spanish speaking families, the response rate was 13%. The average age of the parent (or guardian) responding to the survey was 46.4 years (SD 11.0). The parents were, on average, 34.2 years old when their son or daughter was born (SD 5.8). Parents had, on average, 2.8 children (SD 1.4) with a mean gross household income of

TABLE 1 Characteristics of parent respondents

U.S. cohort		Dutch cohort	
Background variables	%	Background variables	%
Parent role (N = 1,955)		Parent role (N = 669)	
Mother	63	Mother	82
Father	37	Father	18
Marriage status (N = 1,958)		Marriage status (N = 669)	
Married	88	Married	73
Divorced	4	Divorced	6
Unmarried but with partner	3	Unmarried but with partner	17
Widowed	2	Widowed	2
Single	2	Single	3
Age of son/daughter with DS (N = 1,953)		Age of son/daughter with DS (N = 669)	
<5	33	<5	24
≥5 and <10	22	≥5 and <10	23
≥10 and <15	14	≥10 and <15	20
≥15 and <20	10	≥15 and <20	14
≥20 and <25	8	≥20 and <25	11
≥25 and <30	5	≥25 and <30	4
≥30 and <35	3	≥30 and <35	2
≥35 and <40	2	≥35 and <40	0
≥40	2	≥40	1
Biological sex of son/daughter with DS (N = 1,973)		Biological sex of son/daughter with DS (N = 669)	
Male	55	Male	60
Female	45	Female	41
Birth order of son/daughter with DS (N = 1,921)		Birth order of son/daughter with DS (N = 664)	
Only	12	Only	15
Youngest	52	Youngest	46
Between youngest and oldest	16	Between youngest and oldest	15
Oldest	20	Oldest	24
Religious affiliation (N = 1,859)		Religious affiliation (N = 664)	
Protestant	44	Protestant	27
Catholic	35	Catholic	19
Atheist	10	Without religious affiliation	50
Jewish	4	Jewish	0.2
Mormon	3	Mormon	NA
Islamic	NA	Islamic	2
Other	3	Other	3
Multiple	1	Multiple	0.3
Educational level (N = 1,940)		Educational level (N = 667)	
Not graduated from 8th grade	1	Primary or lower secondary education	9
Graduated from 8th grade	2	High school or middle vocational college	32
Graduated from high school	24	Higher vocational college (master's degree)	41
Graduated from college/university	47	University (master's or doctorate)	17
Received a master's degree	20		
Received a doctorate	6		
Living situation (N = 1,953)		Living situation (N = 669)	
Lives with child with DS	93	Lives with child with DS	88
Does not live with child with DS	7	Does not live with child with DS	12
Spanish/Hispanic/Latino (N = 1,939)		Spanish/Hispanic/Latino	
Yes	14	Yes	NA
No	86	No	NA

TABLE 1   (Continued)

U.S. cohort		Dutch cohort	
Background variables	%	Background variables	%
Race (N = 1,886)		Race	
White	89	White	NA
Black or African American	2	Black or African American	NA
Asian	2	Asian	NA
American Indian or Alaska Native	1	American Indian or Alaska Native	NA
Other	5	Other	NA
Multiple	1	Multiple	NA
		Language in family (N = 660)	
		Only Dutch	88
		Dutch and Frisian	2
		Dutch and a regional dialect	6
		Dutch and another European language	3
		Dutch and another non-European language	2
United states where currently living (N = 1,966)		Part of the country where currently living (N = 659)	
Massachusetts	22	North (Drenthe, Groningen, Friesland)	9
California	21	East (Flevoland, Overijssel, Gelderland)	28
Colorado	20	West (Noord- and Zuid-Holland, Utrecht, Zeeland)	40
Georgia	15	South (Limburg, Noord-Brabant)	22
North Carolina	8		
Texas	7		
Other	7		
		Country of birth	
		The Netherlands	97.4
		Another country from the Western world	1.4
		A non-Western country	1.2
		Member of the Dutch Down Syndrome Foundation	
		Currently	82
		Never	9
		Earlier, but not currently	9

Percentages might not add up to 100% due to rounding.
DS = Down syndrome; NA = not asked because not applicable.

$109,815 (SD $89,570). As can be seen in Table 1, there was diversity among geography, Hispanic origin, race, and religion. The majority of parents had received a college/university degree or higher. Most respondents were married mothers. Respondents had sons and daughters with DS of all ages, the majority of them still living at home (Skotko et al., 2011a).

3.1.2 | Dutch cohort

We received 669 responses from parents/guardians. As both fathers and mothers were invited to participate, and 550 mothers responded, this represents at least 550 different families, an estimated 17% response rate of the maximum 3,200 families estimated to have been invited. Most of the parental characteristics were highly similar in both cohorts. The average age of the parent (or guardian) responding to the Dutch survey was 46.2 years (SD 9.1). The parents were, on average, 34.5 years old when their son or daughter was born (SD 5.1). Parents had, on average, 2.6 children (SD 1.2). The Dutch questionnaire did not ask about household income.

3.1.3 | Comparisons between cohorts

Demographic variables were highly similar between the cohorts (Table 1). The age distribution of the children with DS is almost identical. Approximately one-fifth of both cohorts were above age 20 years. Both cohorts contained more men than women, consistent with live birth statistics (Kovaleva, 2002). The distribution of birth order is also similar between cohorts. In both the United States and the Netherlands, 9 out of 10 of the people with DS were still living at home.

Most respondents were married mothers. There were a high percentage of parents with a college or university degree or higher (Table 1). In the Dutch cohort, 58% had a higher vocational college or university degree. According to the Dutch Statistical Office, approximately 45% of people, ages 25–45, in the general Dutch population have a similar higher educational degree (Centraal Bureau voor de Statistiek, 2016c). In the U.S. sample, there were clear racial and ethnic differences by parental educational level. Of the white parents, 76% had a college or university degree or higher, compared to 56% for nonwhite parents. For non-Hispanic and Hispanic parents, this was 77 and 44%, respectively.

Some clear differences nonetheless emerged between the two cohorts. In the U.S. cohort, the percentage of fathers in the respondents is higher (37%) than in the Dutch cohort (18%). The percentage of married parents is higher among the U.S. respondents (88%) than in among the Dutch counterparts (73%), and the percentage "unmarried but with partner" is lower (3% for United States vs. 17% for Netherlands). In the Netherlands, living together outside of marriage is not unusual; as of 2016, 16% of households with children in the general population had unmarried parents (Centraal Bureau voor de Statistiek, 2016b). In regards to religious affiliation, 79% of parents were Christian in the United States, compared to 46% in the Netherlands. In the U.S. cohort, 10% of parents identified as atheist, whereas in the Dutch cohort, 50% reported to not having a religious belief, which mirrors the general population in the Netherlands. As of 2014, 49% of Dutch adults in the general population do not consider themselves to have a religious affiliation, according to studies by Centraal Bureau voor de Statistiek (CBS) (Schmeets & van Mensvoort, 2015).

In both cohorts, there is an underrepresentation of ethnic minority groups. In the U.S. cohort, the percentage of black/African Americans is much lower than what one would expect in a representative cohort of parents of people with DS, as estimated by de Graaf et al. (2016a). In the Dutch cohort, very few parents have a non-Dutch cultural background, as evidenced from the questions about parents' country of birth and language(s) spoken in the family (Table 1).

In the Dutch cohort, around 75% of the people with DS were between 3 and 21 years of age. Geographically, 40% of the people in this age group came from the Western part of the Netherlands (vs. 47% in general population), and 28% came from the Eastern part (vs. 22% in the general population) (Centraal Bureau voor de Statistiek, 2016a). It is possible that there are some differences in DS live birth prevalence between parts of the Netherlands, which might partly explain this difference in geographical distribution between our cohort and the general population. However, the lower than expected percentage from the Western part of the Netherlands might also be consequent to the underrepresentation of parents with a non-Dutch cultural background in this cohort, as the immigrant population often lives in the Western part of the country.

In the Dutch cohort, 82% of the respondents are currently members of the SDS, which is to be expected as the participants were recruited through SDS channels.

3.2 | Perceived health and educational challenges

The percentage of people with DS with no or relatively few parentally perceived health problems (score ≤3 on Likert scale) decreases slightly with age. In the U.S. cohort, 67% of parents whose children were <4 years old felt they had few health problems, whereas 60% of parents whose sons/daughters were >16 years old felt the same. The percentage decreased, from 77 to 59% in the Dutch cohort. In contrast, the percentage of people with significant parentally perceived health problems (score ≥5 on Likert scale) increased with age. In the U.S. cohort, 16% of parents whose children were <4 years felt their sons/daughters had significant health conditions, whereas 25% of parents whose sons/daughters were >16 years old felt the same. The percentages increased respectively from 13 to 19% in the Dutch cohort.

On average, 10% of parents in the United States reported a lot of health problems (score ≥6 on Likert scale); 5% did the same in the Dutch cohort. When analyzed by age subgroups, fewer than 15% of parents reported a score ≥6 in the United States, with the exception of parents whose sons/daughters were over 30 years of age, when this percentage was 17%. In the Dutch cohort, fewer than 10% of parents reported a score ≥6, with the exception of parents whose sons/daughters were over 30 years of age, when the percentage was 13%. However, in our cohorts, the number of people in this oldest age group is relatively small, and aging might play a role in some of these people's health problems.

Parents perceived learning challenges more often than they did health problems in their son/daughter with DS. In both cohorts, the percentage reporting ≥5 increased with the age of the person with DS, while the percentage scoring ≤3 (representing none or only a few problems) decreased. After 12 years of age, the distribution within categories is more or less stable. In this age group, in the U.S. cohort, around 59% of parents reported ≥5, and only 16% reported ≤3. The equivalents from the Dutch cohort were 65 and 11%, respectively.

Perceived health problems and educational challenges correlate, with a Pearson correlation of 0.25 in the U.S. cohort ($p < .001$) and of 0.30 in the Dutch cohort ($p < .001$), implying that people with more health problems also have more educational challenges, too. However, the correlation is not strong, so the combination of no or a few health problems with many educational challenges, or vice versa, will also occur. Out of the other background variables, including race (either divided into the categories listed in Table 1 or binarily as whites versus nonwhites), religion, Hispanic origin, age of the parents, and parental educational level, among others, only the age of the person with DS shows a weak correlation with health problems (Pearson correlation was 0.10 in the U.S. cohort [$p < .001$] and 0.14 in the Dutch cohort [$p < .001$]).

In regard to educational challenges, some background variables were associated, too. In both cohorts, variation in the scores on educational challenges can be explained, in part, by a combination of age, biological sex, and *pos-health* of the person with DS along with the educational level of the responding parent. In the U.S cohort ($R^2 = 0.09$, $F = 45.6$, $df = 4$, $p < .001$), *age of person with DS* has a standardized Beta coefficient of 0.13 ($p < .001$), *biological sex of the person with DS* 0.10 ($p < .001$), *pos-health* 0.25 ($p < .001$), and *parental educational level* 0.06 ($p < .001$). In the Dutch cohort ($R^2 = 0.19$, $F = 38.5$, $df = 4$, $p < .001$), *age of person with DS* has a standardized Beta coefficient of 0.33 ($p < .001$), *biological sex of the person with DS* 0.10 ($p < .001$), *pos-health* 0.27 ($p < .001$), and *parental educational level* 0.08 ($p < .001$). Put another way, people with DS have, on average, more educational challenges as perceived by their parents, if they are older, male, have more perceived health problems, and have parents with a higher educational level.

Alternatively, in the U.S. cohort, the scores on educational challenges can be explained by one more predictor—that is, Hispanic origin. However, if Hispanic origin is added to the regression analysis, educational level loses statistical significance ($p = .084$). If parental educational level is represented by a dichotomized version (i.e., "college or higher" or "less than college"), both Hispanic origin and parental educational level remain significant. In this model, which

(a)

(b)
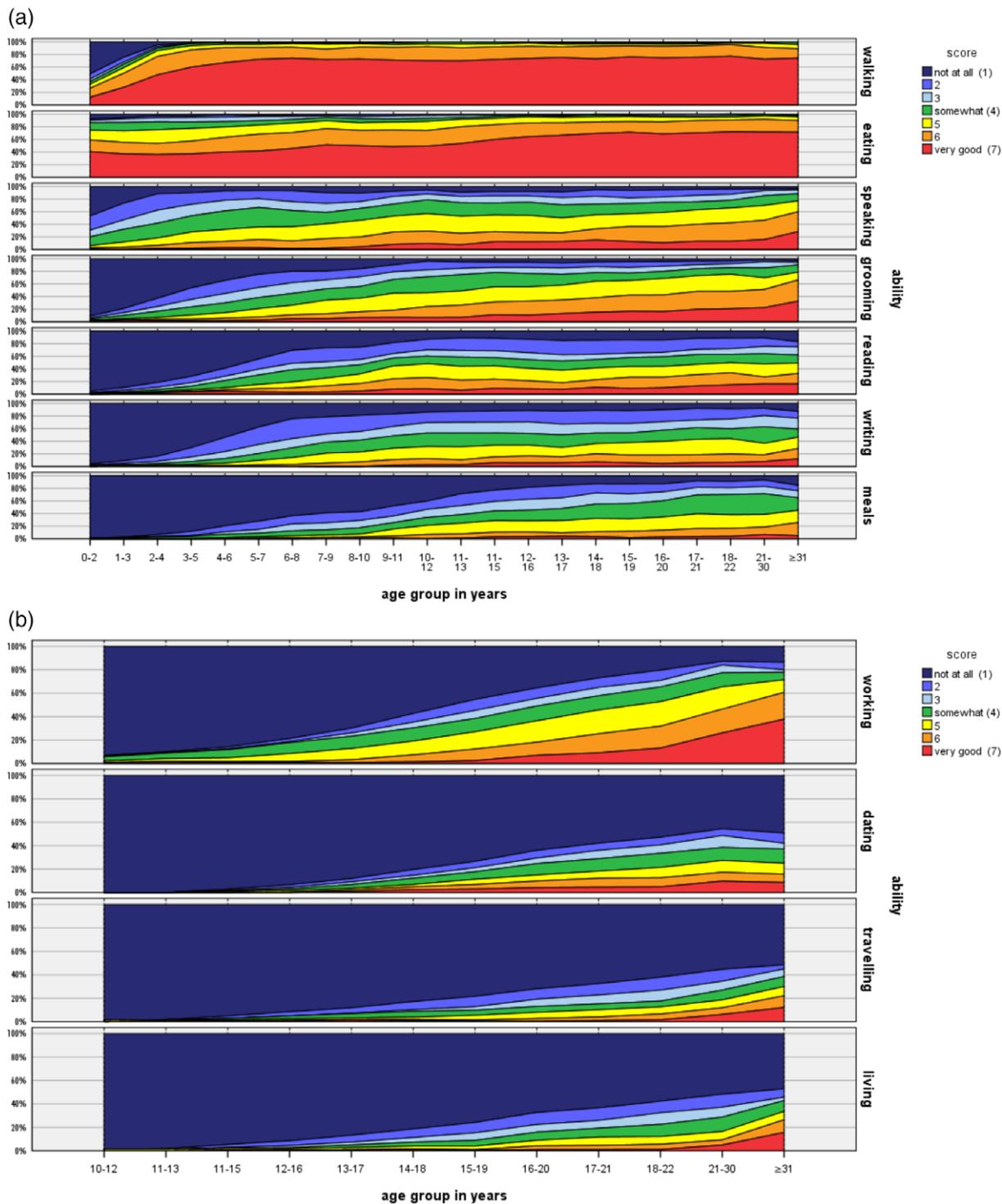
FIGURE 1 (a) Basic functional abilities and academic abilities (U.S. cohort). (b) More advanced functional abilities (U.S. cohort) [Color figure can be viewed at wileyonlinelibrary.com]

predicts slightly more variance, too ($R^2 = 0.10$, $F = 37.6$, $df = 5$, $p < .001$), *age of person with DS* has a standardized Beta coefficient of 0.12 ($p < .001$), *biological sex of the person with DS* 0.10 ($p < .001$), *pos-health* 0.25 ($p < .001$), *parental educational level dichotomized* 0.05 ($p < .026$), and *Hispanic origin* 0.07 ($p < .001$). Put another way, people with DS have, on average, more educational challenges as perceived by their parents, if they are older, male, have more perceived health problems, have parents with a high educational level, and have parents of non-Hispanic origin.

3.3 | Functional abilities for U.S. cohort

In Figure 1a,b, we present the results by age group for the 11 functional abilities in the U.S. cohort. To minimize random fluctuation, which can result from relatively small age groups, we used overlapping age categories. For the Dutch cohort, these detailed results are depicted in Figure S1a,b, Supporting Information.

In the U.S. cohort, eating and walking (Figure 1a) develop early in life. The percentage of parents who reported ≤3 (i.e., less than "somewhat") for eating—a score that suggests codependence for eating—

TABLE 2 Percentiles in months for parental scores ≥5 and percentage reached by adulthood (U.S. cohort)

| | Age in months (and in years; months) when functional skills well achieved at different percentiles | | | | | % with score ≥5 | |
	10%	25%	50%	75%	90%	21–30 years (%)	≥31 years (%)
Walking[a]	15 (1;3)	19 (1;7)	25 (2;0)	32 (2;8)	39 (3;3)	98	96
Eating	–[b]	–	–	24 (2;0)	144 (12;0)	97	96
Speaking	15 (1;3)	55 (4;7)	142 (11;10)	–	–	70	77
Grooming	48 (4;0)	78 (6;6)	156 (13;0)	288 (24;0)	–	70	79
Working	194 (16;2)	204 (17;0)	243 (20;3)	–	–	65	71
Reading	48 (4;0)	97 (8;1)	–	–	–	48	49
Meals	96 (8;0)	180 (15;0)	–	–	–	38	45
Writing	78 (6;6)	132 (11;0)	–	–	–	37	46
Dating	210 (17;6)	276 (23;0)	–	–	–	27	25
Traveling	240 (20;0)	336 (28;0)	–	–	–	19	30
Living	240 (20;0)	342 (28;6)	–	–	–	16	34

[a] The skills are ordered by the results in the column 21–30 years of age, from the highest to the lowest percentage.
[b] If no value is reported, either the starting point in the youngest age group was above the specific *p*-value, or in using the regression line, the specific *p*-value is not fully reached.

decreases from 13% in the first years of life to 5–9% in primary-school aged children to less than 3% above 12 years of age. For walking, in children <3 years of age, 33% walk at least reasonably well (score ≥5), increasing to about 59% for the age group 1–3 years of age, to 86% for the age group 2–4 years of age, and to more than 98% for children older than 4. More likely than not, children with DS are walking by 25 months, as perceived by their parents (Table 2; Figure 3). A score of 1–3 (less than "somewhat") is 63% in the age group 0–2 years of age (Figure 1a), decreasing to 35% in age group 1–3, to 10% in age group 2–4, less than 3% in all age groups above, and less than 1% in (mostly young) adults.

The development of speaking begins early, too, but continues into adulthood (Figure 1a). Per parental report, the percentage of persons with DS who speak at least reasonably well (score ≥5) goes up from 6% between 0 and 2 years of age, to 10% in the age group 1–3 years of age, to 28% between 3 and 5 years of age, to >50% at 9 years of age and over, and to 70% in young adults (21–30 years of age). According to our regressions used in estimating the percentile scores, more likely than not, children with DS are speaking reasonably well by 12 years of age, as perceived by their parents (Table 2; Figure 4). A score 1–3 (less than "somewhat") applies to 80% in the age group 0–2 years, decreasing to 47% in the age group 3–5, to 20–30% in older children and adolescents, to around 15% in young adults (21–30 years of age), which still is a substantial minority (Figure 1a).

Per parental report, the percentage of persons with DS who can reasonably well take care of their own grooming and self-hygiene (score ≥5) goes up from 11% in ages 3–5, to around 50% in young teenagers (10–15 years of age), and to 70–80% in adults (≥21 years of age) (Figure 1a). More likely than not, people with DS can reasonably take care of their own grooming and self-hygiene by 13 years of age (Table 2). In adults, a score of ≤3, which suggests a need for significant support in grooming, is found in <15% of persons (Figure 1a).

In the youngest age groups, there are a few children who, according to their parents, can read and/or write at least reasonably well (score ≥5) (Figure 1a). For children 4–6 years old, 10% can read at least reasonably well according to their parents, and 22% can read at least "somewhat" well (score ≥4). In the primary school years, reading

develops rapidly. Between 10–12 years of age, almost 50% can read at least reasonably well, and 60% can read at least somewhat well. These percentages stay more or less constant in adolescence and adulthood. The percentage that reads very well (score of 7) still increases in the teenage years from 9% in ages 10–12 to 16% in young adults (21–30 years of age).

In almost all age groups, reported scores for writing are lower than those for reading. For children ages 10–12, 53% write at least somewhat well (score ≥4), and 32% are reported to write at least reasonably well (score ≥5), and 3% very well (score 7). In the teenage years, these percentages increase to, in young adulthood (21–30 years of age), respectively, around 40% writing at least reasonably well (score ≥5), around 60% at least somewhat (score ≥4), and 8% very well (score 7).

In early childhood, only very few parents report that their children are preparing their own meals (Figure 1b). For children ages 3–5 years, 4% do this at least somewhat well (score ≥4), and this percentage increases to 26% in the age group 9–11, around 50% in teenagers (11–20 years of age), to around 70% in young adulthood (21–30 years of age). Preparing meals at least reasonably well (score ≥5), goes up from 15% in the age group 9–11, to around 30% between 11 and 20 years of age, to around 40% for young adults (21–30 years of age).

The development of working ability begins in young teenagers (Figure 1b). Within the age group of 10–12 years, 6% of parents reported a score of at least somewhat (score ≥4), and 2% at least reasonably well (score ≥5). These percentages increase during later years, with 77% of parents of parents reporting a score ≥4 and 65% a score ≥5 by young adulthood (defined here and throughout as 21–30 years of age). More likely than not, people with DS are working at a reasonably well level by 20 years of age, as perceived by their parents (Table 2). Dating also begins in the late teenage years and continues into young adulthood (Figure 1b). In the age group 14–18, 12% of parents report that their son or daughter at least somewhat dates (score ≥4), and 7% report that their sons/daughters at least date reasonably well (score ≥5). These percentages increase to around 40% (score ≥4) and around 25% (score ≥5), respectively, in young adulthood (21–30 years of age).

(a)
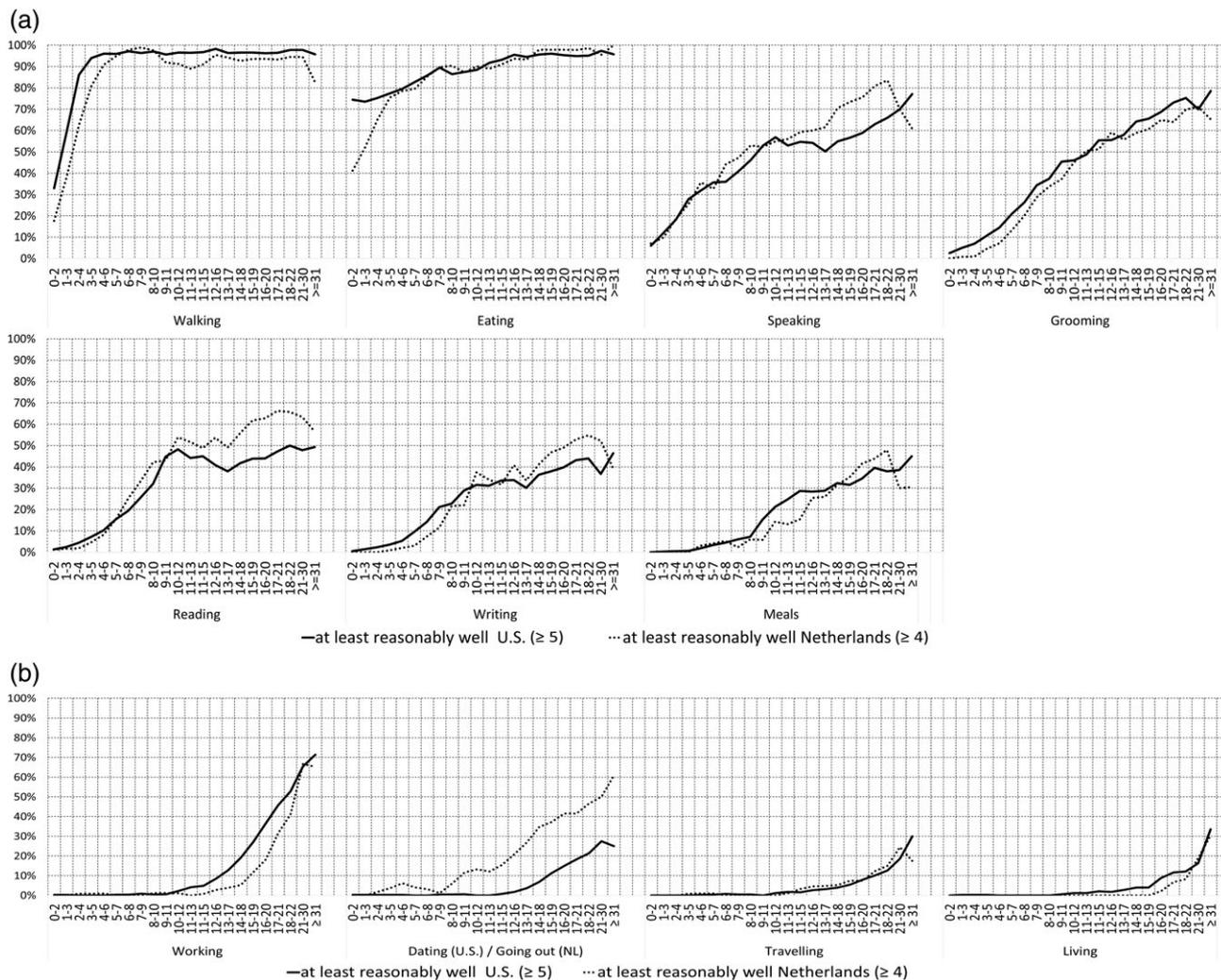
FIGURE 2 (a) Basic functional and academic abilities achieved, at least, reasonably well in both the U.S. and Dutch cohorts. (b) More advanced functional abilities achieved, at least, reasonably well in both the U.S. and Dutch cohorts

In late adolescence, parents also begin to report that their sons/daughters begin to develop the skills to live and travel independently. In people with DS ages 16–20 years, 8% are reported by parents to have, at least, reasonably well-developed skills in independent living, and 16% at least "somewhat" developed skills. Skills for independent traveling are 9 and 13%, respectively. Later, in young adulthood (21–30 years of age), the percentage of people with DS reported by parents to have, at least, reasonably well-developed skills for independent living is at 16%, and 29% at least "somewhat" developed skills. Skills for independent traveling are 19 and 27%, respectively. For older adults
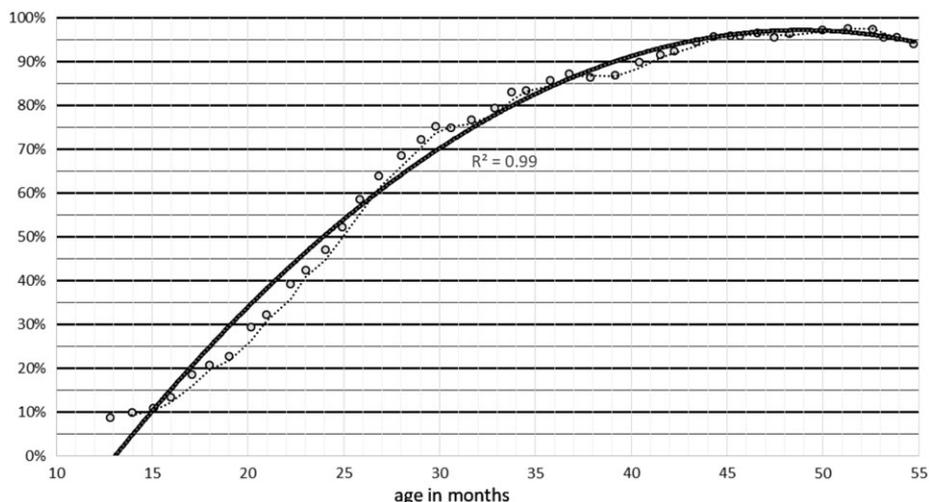
FIGURE 3 Walking at least reasonably well by age in months (U.S. cohort)
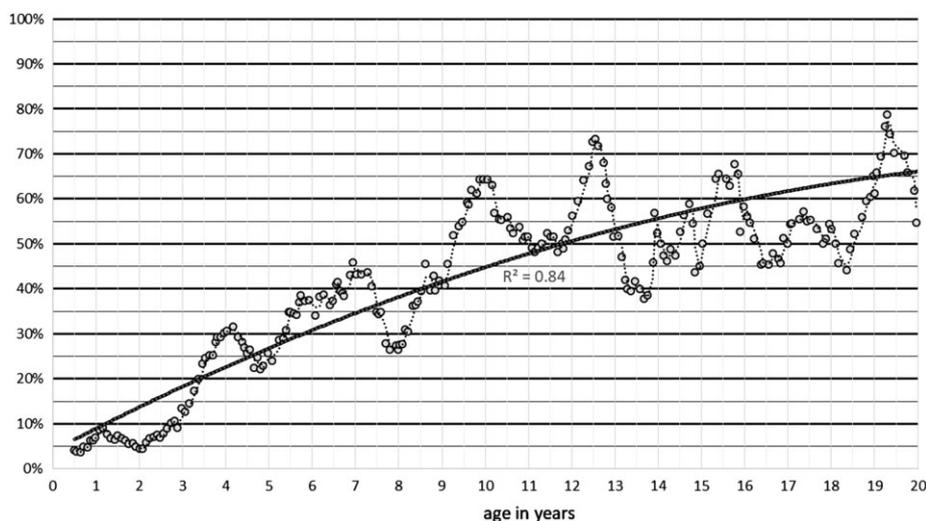
FIGURE 4 Speaking at least reasonably well by age in years (U.S. cohort)

(≥31 years of age), these percentages are still higher: independent living at 34% (score ≥5) and 43% (≥4) and independent traveling at 30 and 39%, respectively.

3.4 | Similarities and differences in functional abilities in the two cohorts

The results of the two countries cannot be compared directly due to the limitations of translation. However, if we assume that the U.S. category "4" ("somewhat") is similar to the Dutch category "3" ("matig," meaning "not too much"), we could compare—as an equivalent for "can do the ability at least reasonably well"—the percentage in the Categories 5–7 in the U.S. cohort to the percentage in the Categories 4–7 in the Dutch cohort. In Figure 2a,b, these results are presented. There appears to be a striking similarity for most developmental areas, with similar trends by age and similar differences between skill areas. However, there seem to be some differences too. In the first years of life, Dutch parents seem to be less optimistic in evaluating the development of their child's walking and eating skills, though by age 5, the developmental lines of both countries coincide. Also, in comparison to their U.S. counterparts with DS, age 12–21 (and, for reading, into adulthood, too), the Dutch parents reported higher scores on reading and speaking skills, and, to a lesser extent, on writing, as well. In contrast, during the teenage years, U.S. parents appear to be more optimistic about the development of working skills and skills for independent living, with higher percentages scoring "reasonably well" between 12 and 21 years of age, though the Dutch seem to catch up in young adulthood (21–30 years of age).

3.5 | Percentile values in the U.S. cohort

In Table 2, we present the percentile of children with DS achieving different abilities, at least reasonably well, as assessed by their parents. Figures 3 and 4 illustrate two of these skills: walking and speaking. In addition, Table 2 shows which percentage has scored ≥5 in the age groups 21–30 years and ≥ 31 years of age, respectively.

3.6 | Composite functional activity score and *dq-functional*

Cronbach's alpha for the composite functional activity score is 0.89 (U.S. cohort) and 0.90 (Dutch cohort). In both cohorts, *dq-functional* has a mean value of 100 (*SD* = 22.4, U.S. cohort; *SD* = 22.8, Dutch cohort).

In both cohorts, variation in the scores on *dq-functional*, which is a measure of the position of the person in relation to same-aged peers with DS from their own country, can be explained by the same set of variables—that is, *pos-educational*, *pos-health*, biological sex of the person with DS, and the educational level of the responding parent, with standardized Beta coefficients being highly similar in both countries. In the U.S cohort (R^2 = 0.19, F = 104.2, df = 4, p < .001), *pos-educational* has a standardized Beta coefficient of −0.30 (p < .001), *pos-health* −0.20 (p < .001), *biological sex of the person with DS* −0.10 (p < .001), and *parental educational level* 0.11 (p < .001). In the Dutch cohort (R^2 = 0.18, F = 36.6, df = 4, p < .001), *pos-educational* has a standardized Beta coefficient of −0.29 (p < .001), *pos-health* −0.20 (p < .001), *biological sex of the person with DS* −0.10 (p < .001), and *parental educational level* 0.12 (p < .001). In other words, in both countries, in comparison with same-aged peers with DS, people with DS, on average, score higher on functional skills if their parents also report that their son/daughter with DS has relatively few educational challenges and health problems, particularly if the person with DS is also female and the parents have a higher educational level. There were no other statistically significant predictors. Alternatively, though, for the U.S. cohort, *dq-functional* can be predicted by *Hispanic origin*, *pos-educational*, *pos-health*, biological sex of the person with DS. *Hispanic origin* loses statistical significance, however, once parental educational level is added to the modeling.

4 | DISCUSSION

4.1 | Walking

In this survey, 2,658 parents from the United States and the Netherlands combined reported the functional skills of their sons and

daughters with DS. According to U.S. parents, the majority of children with DS are walking by 25 months of age, similar to previous research (Palisano et al., 2001). Dutch parents reported that 36% could walk reasonably well by age 2 and 70% by age 3. Thus, in the first years of life, the Dutch parents reported slower acquisition of walking; though by age 5, this difference disappeared. Both in the United States and the Netherlands, children with DS are afforded free physical therapy services, beginning at birth, through Early Intervention services. While physical therapy may speed up the acquisition of gross motor skills, the goal of therapy is focused on correcting abnormalities that may cause compensatory strategies that will lead to long-term postural and functional abnormalities (Lauteslager, 2000; Winders, 2001). As such, variances in physical therapy services might not account for the apparent differences in the age of walking in children with DS living in the United States and the Netherlands.

4.2 | Speaking

According to U.S. parents, the majority of children with DS were speaking with comprehensibility by 12 years of age. This is consistent with previous reports documenting initial delays in intelligibility and improvement with age (Kent & Vorperian, 2013; Kumin, 2006). Up until 12 years of age, no apparent difference existed in the development of speaking between the U.S. and the Dutch sample. Previous research has demonstrated that young children who received speech-language interventions increased the size of their expressive vocabulary (signed and/or spoken) and their rate of word usage (signed and/or spoken) (Roberts, Price, & Malkin, 2007; Wright, Kaiser, Reikowsky, & Roberts, 2013). In comparison to their U.S. counterparts who had children aged 12–21, however, the Dutch parents reported higher scores on speaking skills, reading skills, and, to a lesser extent, writing skills. Early intervention services in the United States were federally mandated later, in 1986, for children under the age of 3 years (Center for Parent Information and Resources, 2012). Similarly, before the mid-1980s, in the Netherlands, early intervention services were absent, and children with DS had no access to regular education. In recent years, around 68% of the parents of young children with DS in the Netherlands make use of an early intervention program, and around 60% of these parents receive professional support in working with such a program (de Graaf, de Graaf, & Borstlap, 2011).

Language development, of course, depends on opportunities to learn beyond early Intervention services. In 1975, the Individuals with Disabilities Education Act was enacted in the United States, enabling all people with disabilities, including DS, to have access to a free an appropriate education in the least restrictive environment (Center for Parent Information and Resources, 2012). To the extent that children with DS are in deprived language environments surrounded by peers with limited language, have scant access to literacy in their school curricula, and/or participate in fewer conversational experiences due to fewer initiations, intelligibility will naturally lag. Access to language-rich opportunities for people with DS certainly vary by country and might explain part of the difference in this age group. Differences in the speech sound system (phonotactics) between the Dutch and English languages might also explain some differences. Additionally or

alternatively, Dutch parents in this age group might have a generally more favorable perception of their adolescents' skills.

In 1994, Kumin, 1994 collected 937 questionnaires from parents who had children with DS in the United States, and over 50% of them reported that their children had frequent intelligibility difficulties across every age group. Our more recent data suggest that increased access to speech and language therapy might have contributed to the improved parent-reported intelligibility outcomes. A recent survey of 161 U.S. families concurs, with only 15% of families indicating that their adults with DS had "a lot of difficulty" being understood by others (Matthews et al., 2018). Similarly, parents in Rome, Italy, reported that the majority of people with DS, ages 14–62, had little to no difficulty making themselves be understood (Bertoli et al., 2011).

4.3 | Reading

By 21–30 years of age, approximately 48% of adults with DS in the United States and 63% in the Netherlands from our study could read reasonably well, as reported by their parents. A previous study in the United States found that about 35% of adults had some difficulty with reading comprehension and 35% had a lot of difficulty (Matthews et al., 2018). According to parents in Rome, approximately 52% of people with DS could read easily by age 20–24 and 36% by age 25–30. Parents in Canada estimated in 2003 that about 68% of their adults with DS, ages 19 and older, were at least reading at the third-grade level (Trenholm & Mirenda, 2006). Both word recognition and language comprehension are important, interacting elements to achieve meaningful reading (Burgoyne, Baxter, & Buckley, 2014). Some parents in our survey might have been responding with only word recognition in mind, as this measure is more easily quantified and recognized. Evidence from inclusionary classrooms where students with DS have access to regular literacy instruction suggests that up to 90% of children with DS have sufficient word recognition to enable reading (Burgoyne et al., 2014). Comprehension, however, remains an area of significant challenge for many persons with DS, often related to corresponding challenges in language and verbal memory.

4.4 | Writing

By 21–30 years of age, approximately 37% of adults in the United States and 52% in the Netherlands could write reasonably well. Similarly, a previous U.S. study found that 33% of parents felt that their adults with DS could "write to communicate" (Matthews et al., 2018). In Rome, approximately 52% of people with DS could write easily by age 20–24 and 49% by age 25–30 (Bertoli et al., 2011). In a 2003 survey of Canadian families, the majority of adults with DS, ages 19 and older, were rated by their parents as having functional writing activities, such as making lists (65.9%), writing notes to relay messages (68.3%), or writing names or other familiar words (68.3%) (Trenholm & Mirenda, 2006).

Parents on our surveys might have responded with different understandings of "writing" in mind: some assessing legibility, whereas other could have been assessing composition. Variations in reading and writing skills between countries might also reflect differences in

educational systems, parental expectations, or both (de Graaf & de Graaf, 2016). The current adults with DS also had very different educational opportunities in both the United States and the Netherlands, when compared to their younger counterparts. Now, more than ever before, children with DS are educated in "inclusion" classrooms, side-by-side with their neurotypically developing peers. When proper supports are also in place, children with DS are achieving better academic gains in inclusion program than their counterparts are in substantially separate classrooms (Buckley, Bird, & Sacks, 2006; Buckley, Bird, Sacks, & Archer, 2006; Casey, Jones, Kugler, & Watkins, 1988; de Graaf & de Graaf, 2016; de Graaf & van Hove, 2015; de Graaf, van Hove, & Haveman, 2012; de Graaf, van Hove, & Haveman, 2013; Sloper, Cunningham, Turner, & Knussen, 1990; Turner, Alborz, & Gayle, 2008). To this extent, the best in functional skills might be yet to come, as the younger cohort grows up.

4.5 | Eating

Nearly 97% of adults with DS in the United States and 96% in the Netherlands are eating reasonably well by adulthood, according to their parents. Previous work documented that the majority of people with DS mastered the skill of feeding themselves with a fork by 5.5–7.5 years of age (Frank & Esbensen, 2015). In another recent U.S. study, about 89% of parents felt their adults with DS could eat their meals independently (Matthews et al., 2018). Our study assessed the more global, functional skill of eating, in general, which could encompass motor skills, nutritional intake, and self-independence.

4.6 | Meal preparation

By 31 years of age, approximately 45% of adults with DS in the United States and 30% in the Netherlands were preparing their own meals. Similarly, in another U.S. study, about 57% of parents report their adults with DS could prepare simple meals (Matthews et al., 2018). In Rome, only 20% of adults were reported to have little to no difficulty preparing their own meals (Bertoli et al., 2011). These intercountry and intergenerational variations can reflect cultural differences in family expectations, differences in life skill training at schools, or both.

4.7 | Self-hygiene

According to our surveyed parents, the majority of people with DS can reasonably take care of their own grooming and self-hygiene by 13 years of age in the United States, a similar development in both the Dutch and U.S. cohort. By age 21–30, about 70% in the U.S. cohort and 71% in the Dutch cohort can take reasonable care of grooming and self-hygiene. Similarly, about 68% of parents reported that their adults with DS had no difficulty with grooming (Matthews et al., 2018), and about 75% of people with DS ages 14–19 in Rome have little to no difficulty washing themselves (Bertoli et al., 2011). Previous work has demonstrated that considerable progress in self-help skills can be gained in teenage years and beyond in persons with DS (Buckley, Bird, Sacks, & Archer, 2002).

4.8 | Employment

By 31 years of age, about 71% of adults with DS in the United States and 65% in the Netherlands are working at a job, however, defined by their parents. According to a different survey of 511 households in the United States, about 57% of adults with DS, ages 18 and older, were currently in a paid job, most usually part-time (Kumin & Schoenbrodt, 2016). The most usual jobs were in restaurant/food services, janitorial services, landscaping, and office work. In another U.S. study, 55% of parents reported that their adults with DS worked at least 7 days each month (Matthews et al., 2018). In Rome, about 19% of adults ages 31–35 worked often, including in sheltered workshops (Bertoli et al., 2011). These differences likely reflect varying parental expectations and social opportunities for adults with DS in different countries.

4.9 | Dating and going out

Socially, by 31 years of age, about 25% of adults with DS in the United States are going on dates. In the Dutch survey, dating was translated with "uitgaan," more akin to "going out," which can be applied not only to romantic dating but also to going out with friends. As such, different constructs were likely measured, and a direct comparison between the U.S. and Dutch data is not appropriate. In the Dutch sample, by age 31 years of age, about 61% of the adults with DS had reasonably well-developed skills related to "going out." In comparison, in Rome, about 20% aged 31–35, often "went out with friends." In another U.S. survey, 32% of adults with DS "hang out with their friends at least seven times each month (Matthews et al., 2018).

4.10 | Independent travel and living

By 31 years of age, about 30% of adults with DS in the United States, and 17% in the Netherlands could travel independently. However, in the age group 18–22 years of age, this was 24% in the Netherlands. In Rome, about 19% of adults aged 31–35 and 24% aged 36–40 had little to no difficulty using a bus or metro. By 31 years of age, about 34% of adults with DS in the United States and 30% in the Netherlands were living independently. No previous studies that we are aware of have reported this metric by age.

4.11 | Overall learning and functional abilities

In both the United States and the Netherlands, parents perceived more learning challenges as their son or daughter with DS got older. This might be explained by the fact that in young children with DS, developmental differences with peers without DS are less pronounced than later in life. Parents who came from higher educational backgrounds were also more likely to perceive their sons or daughters with DS as having more educational challenges in comparison to the children with DS whose parents had a lower educational background. Yet still, the children with DS whose parents had a higher educational background had relatively well-developed functional skills. One explanation might be that such parents have higher academic expectations for their children with DS when compared to their counterparts with lower educational backgrounds. Additionally or alternatively, parents

with higher educational background might perceive a stronger need for support or be driven by a stronger sense of urgency. Such parents might be able to mobilize more supports and resources, leading to, on average, better functional skills for their child with DS. If such were to be the case, social inequities might contribute to functional differences in people with DS. Parents of Hispanic origin perceived their child as fewer having educational challenges as compared to parents of non-Hispanic origin, already taking into account that Hispanic parents had, on average, a lower parental educational level.

In our sample, there was no statistically significant effect of parental racial group on the level of functional abilities; however, the nonwhite group is so small (and diverse) that small differences might not have been detectable. However, our research does show that the children of parents with a higher parental educational level more often have well-developed functional abilities. Importantly, in our sample there exist clear differences in parental educational level between racial/ethnic groups. In the modeling for the U.S. cohort, *dq-functional* could be predicted by *pos-educational*, *pos-health*, biological sex of the person with DS, and *Hispanic origin*, suggesting some ethnic differences in level of functional abilities. However, adding parental educational level leads to *Hispanic origin* loosing statistical significance, implying that these ethnic differences in level of functional abilities are explained more by differences in parental educational level between Hispanics and non-Hispanics.

Some earlier studies on children with DS in the United States and the Netherlands also demonstrated that access to medical services and/or inclusive educational settings can be impacted by ethnic/racial disparities and/or disparities by parental educational (Centers for Disease Control and Prevention, 2015; Koopman, van Eck, & de Boer, 2018; Kozleski, 2009; Kucik, Shin, Siffel, Marengo, & Correa, 2013; Wang, Liu, Canfield, et al., 2015). These social inequities might explain some of the differential developmental outcomes. In the United States, there is some evidence that survival rates for young children with DS differ by race/ethnic group, with less favorable outcomes for non-Hispanic blacks and for American Indians/Alaska Natives, though the gap is narrowing in more recent years (Centers for Disease Control and Prevention, 2015; Kucik et al., 2013; Wang et al., 2015). Differences in access to high quality medical services might also play a role. In regards to educational opportunities, a U.S. study from 2009 on the educational placement of students with severe disabilities showed that African American, Hispanic, and Native American students are more likely to be placed in more segregated educational settings than white students who have the same disability (Kozleski, 2009). According to a report in 2018 by the National Council on Disability in the United States:

> "Students with disabilities, in particular students of color and students in urban settings, as well as students with specific disability labels (such as autism or intellectual disability), continue to be removed from general education, instructional, and social opportunities and to be segregated disproportionately when compared to White students who live in suburban and rural areas and those who have less intensive academic support needs" (National Council on Disability, 2018).

Georgia, for example, has a constellation of public schools known at the Georgia Network for Educational and Therapeutic Support, which have come under intense scrutiny for their segregated and punitive treatment of black students with disabilities (Aviv, 2018).

A Dutch study demonstrated that children with DS who had parents with a lower educational level more often were transferred from regular education to segregated special schools (even after controlling for child characteristics) compared to parents with a higher educational level (de Graaf et al., 2013). A recent Dutch study corroborates this social inequity. Up through the school years, children with DS of parents with a higher educational level were much more likely to be in inclusive educational environments than children with DS of parents with a lower educational level (Koopman et al., 2018). Regarding the access to early intervention services for children with DS, it is possible that similar social inequities exist; however, we are not aware of any research studies that systematically explored these possibilities in either country.

Some parents reported that, by adulthood, their sons and daughter had still not reasonably achieved some of the functional skills. This has several implications. First, this subset of adults with DS might have more complex cooccurring health issues (e.g., autism spectrum disorder), which complicate the attainment of these functional skills. In our data, there is a correlation between perceived health problems and perceived learning difficulties and between perceived health problems and the extent to which the persons have developed skills, according to their parents. Second, variations of and accessibility to education/therapy might account for some of the differences. Finally, or in combination, this subset of adults with DS might have more significant intellectual disabilities. Even with sufficient therapies, supports, and education, some people with DS might have lower intellectual abilities, making it more challenging to master certain functional skills. Parents should be discouraged from taking on blame or feeling inadequate in such circumstances, as the attainment of these functional skills might be more reflective of genetic limits, rather than parental and societal supports.

Our research is not without limitations. The study is subject to selection bias, as the participating parents were recruited through not-for-profit organizations. However, no population-based registries yet exist for people with DS in the United States or the Netherlands. The United States has begun to create a registry of parent-entered data (DS-Connect: dsconnect.nih.gov/); a registry is still lacking, but needed, in the Netherlands. Our results are also limited by the lack of racial diversity of our respondents. In the Dutch cohort, very few parents have a non-Dutch cultural background. The U.S. cohort did not include many black/African American, Asian, American Indian, or Alaska Native Americans. Our results did, however, proportionately represent Spanish/Hispanic/Latino Americans. Until DS not-for-profit organizations diversify their membership or more robust population-based registries are created, epidemiological studies will continue to have these limitations. Our results nonetheless represent the opinions of more than 2,600 parents, making it the largest of its kind, to date.

Our findings might also overrepresent parents who have a college or university degree. This might be expected, though, as the chance for a child with DS strongly increases with maternal age, and high

educational background is associated with postponed motherhood (Mills et al., 2011). In the United States, for instance, between 2003 and 2006, around 27% of all children were born to mothers with 16 years of education or more (United States Department of Health and Human Services (US DHHS), Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS), Division of Vital Statistics, 2017). Absent selective terminations, this percentage would be 40% in the mothers of children with DS based on estimates of maternal ages in births in general population by years of education of the mother (United States Department of Health and Human Services (US DHHS), Centers for Disease Control and Prevention (CDC), National Center for Health Statistics (NCHS), Division of Vital Statistics, 2017) and maternal-age related chance for a live birth of a child with DS, following the method of de Graaf et al. (de Graaf et al., 2011; de Graaf, Buckley, Dever, & Skotko, 2017; de Graaf, Buckley, & Skotko, 2015b; de Graaf, Buckley, & Skotko, 2016b). However, differential usage of prenatal screening and selective terminations between maternal age groups and, perhaps, maternal educational levels, will probably temper this effect. As such, our large percentage of parents with a higher educational level probably reflects more on the differential membership of DS not-for-profit organizations and/or differential response rates between parent educational levels. However, both in our U.S cohort and Dutch cohort, the average maternal age at birth of the child with DS was higher in mothers with a college or university degree (respectively, 34.1 for the U.S. cohort and 34.3 for the Dutch cohort) than in mothers with a lower educational level (respectively, 33.0 and 33.8), suggesting there still might be some effect on prevalence of the higher maternal ages in mothers with a higher educational level.

The way in which we have estimated the percentile scores has certain limitations. First, for some skills, a 50th or 75th percentile cannot be established; not enough parents reported that their adult sons and daughters had learned to master some skills reasonably well. In contrast, for eating, a 10th, 25th, and 50th percentile cannot be estimated, as far more than 50% of parents reported that their child was eating well, even at a very young age, likely meaning that breast- or bottle-feeding was going fine. A final limitation is that for functional skills where the 50% of children score "reasonably well" for longer time periods, our regressions will lead to a sharp cutoff point halfway during this time period, suggesting a very clear-cut 50th percentile. (The same could be true when 25% or 75% were scoring "reasonably well" for longer time periods.) Alternatively, one could instead say that there was a long transition period with a kind of temporary plateau for that skill. We argue that using our regression approach levels out the random differences which inevitably will occur in shorter age groupings, and thus leads to a more accurate estimation of percentile scores.

In previous research, the overwhelming majority of people with DS in the United States have indicated that they are happy, like who they are, and like how they look (Skotko, Levine, & Goldstein, 2011b). Yet, prenatal testing has sharpened the focus, more than ever before, on the functional abilities of people with DS. This survey of parents from the United States and the Netherlands answers those charges, in part, for expectant parents. Yet, these developmental milestones can also serve as helpful guideposts for current parents, therapists, and clinicians who would like to assess the relative functional skills of a person with DS. Additional supports, resources, and therapies might be marshaled, for example, when a person with DS is falling behind his or her counterparts with DS reported here. Above all, the person with DS never stops learning, as functional skills can still be attained well into adulthood

AUTHOR DISCLOSURE

B.G.S. occasionally consults on the topic of DS through Gerson Lehrman Group. He received remuneration from DS nonprofit organizations for speaking engagements and associated travel expenses. B.G.S. and S.P.L. received annual royalties from Woodbine House, Inc., for the publication of their book, *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters.* Within the past 2 years, B.G.S. has received research funding from F. Hoffmann-La Roche, Inc., and Transition Therapeutics to conduct clinical trials on study drugs for people with DS. B.G.S. is occasionally asked to serve as an expert witness for legal cases where DS is discussed. G.de G. works for the Dutch DS Foundation, a nonprofit organization. S.P.L. works for Family Resource Associates, a nonprofit organization.

CONFLICT OF INTEREST

Beyond the items mentioned in the financial disclosures above, B.G.S. serves in a non-paid capacity on the Honorary Board of Directors for the Massachusetts Down Syndrome Congress, the Board of Directors for the Band of Angels Foundation, and the Professional Advisory Committee for the National Center for Prenatal and Postnatal Down Syndrome Resources. B.G.S. has a sister with DS. G. deG had a daughter with DS, who passed away in 2005 at the age of 15.

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SUPPORTING INFORMATION

Additional supporting information may be found online in the Supporting Information section at the end of the article.