



Description of School-Based Physical Therapy Services and Outcomes for Students with Down Syndrome

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Published online: 17 June 2019
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Abstract

Students with Down syndrome (DS) receive school-based physical therapy (SBPT), however little data exists regarding services and outcomes. Using a prospective observational cohort study our aim was to explore SBPT activities and interventions, and students' goal achievement of 46 students with DS, tracked by 17 physical therapists (PTs). PTs provided on average 24.0 min/week direct service and 11.6 min/week services on behalf of the student. The most frequent activities employed were physical education/recreation, mobility, and sitting/standing/transitions. The most frequent interventions implemented were neuromuscular, mobility, and musculoskeletal. Although students individually met 69.5% of their primary outcome goals, their achievement could not be explained by total minutes of either direct and minutes on behalf of SBPT, nor minutes spent in most frequent activity.

Keywords Down syndrome · School-based physical therapy · School function assessment · Goal Attainment Scaling · Outcomes

As part of a student's Individualized Education Program (IEP) team, physical therapists (PTs) as related services providers, support the student's participation in school, recreation, and extra-curricular activities (Effgen and Kaminker 2017). IDEA (2004) requires service interventions to be "based on peer-reviewed research to the extent practicable ((§300.320(a)(4))." Effgen and McEwen (2008) reviewed interventions therapists provide in the educational setting and concluded most interventions need more research to be considered effective in improving functional status of students. No current research could be found regarding school-based physical therapy (SBPT) services with specific pediatric populations like Down syndrome (DS).

When school-based PTs consider services for students, they must consider which evidence-based interventions to implement, and location and methods of service delivery. Location of services in schools are typically either within the classroom supporting the participation of the student with peers, or in an isolated setting (Effgen and Kaminker 2014). Although most school-based physical therapists (SBPTs) agree that services within the student's inclusive educational settings are ideal they frequently provide services in isolated locations (Effgen and Kaminker 2014). For students with DS, this isolated service location can be challenging because they often struggle to generalize skills learned in isolated settings into natural environments (Winders 2001).

Another factor SBPTs must consider is service methodology. Services are provided either directly with the therapist and student working together, or in a consultative manner where the therapist is providing direction and input to other school personnel or caregivers on behalf of the student. Effgen and Kaminker (2017) stated direct services were considered more appropriate when new skills were being taught and consultative services were usually more appropriate for carryover of the skill into the classroom. Additionally, SBPTs provide services "on behalf" of the students such as documentation, collaboration, and participation in IEP meetings, that are important components of practice.

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One technique for examining current practice and outcomes, without altering services, is through observational research such as practice-based evidence (PBE) methodology (Horn et al. 2005). In PBE studies, researchers collect data on patient outcomes, key patient characteristics and interventions to describe services; however, there is no manipulation of the services provided. The PBE methodology permits the exploration of services while allowing for individual and intervention variability; therefore PBE may support researchers in identifying specific services therapists are currently providing in school programs (Horn et al. 2012; Horn and Gassaway 2010).

Effgen et al. (2016) completed a PBE study, *PT related Child Outcomes in the Schools* (PT COUNTS), examining SBPT services and outcomes for students with disabilities. Results indicated students most frequently received neuromuscular, musculoskeletal, mobility, and educational interventions, and therapists focused on physical education (PE)/recreation, mobility, and pre-functional activities (Jeffries et al. 2018). Additionally, most students achieved or slightly exceeded their expected goal attainment for their primary goal, as measured by individual Goal Attainment Scaling (GAS) (Chiarello et al. 2016). Based on the results of the PT COUNTS study, the aim of this study was to examine SBPT services and student outcomes, and to determine if any correlation existed between services and outcomes for students with DS. The research questions investigated included:

1. During 20 weeks of SBPT, what services, activities, and interventions do physical therapists provide to students with DS?
2. Is an increase in the time (minutes) of direct services students with DS receive associated with meeting or exceeding their primary goal using Goal Attainment Scaling (GAS)?
3. Do students with DS who achieve their GAS goals receive greater intervention time (minutes) spent working on sitting/standing/transfers, mobility, and PE/recreation activities?
4. For students with DS, do their School Function Assessment (SFA) subtest scores change in the areas of travel, maintaining and changing positions, manipulation with movement, and recreational movement following 20 weeks of SBPT?
5. For students with DS, are age, gender, and functional mobility level, based on the Gross Motor Functional Classification System (GMFCS), significant covariates with SFA change score?

Methods

This prospective, multisite, longitudinal observational practice-based evidence (PBE) study is part of a national study of SBPT services and outcomes, PT COUNTS, using a PBE methodology (Effgen et al. 2016). This study focused on a convenience sample of the 46 students with DS who were participants in the PT COUNTS study. For the PT COUNTS study, inclusion criteria were students in kindergarten through sixth grade, no history of a progressive disorder, no plans of moving or having major surgery during the school year when investigators collected data, and had not been absent from school more than 30% of the time the previous school year (Effgen et al. 2016).

Physical therapists, with at least 1 year of SBPT experience, who completed online training identified students who met the inclusion criteria from their workload and provided a coded list of these students to researchers (Effgen et al. 2016). Investigators wanted participating students to be distributed across therapists so they limited each therapist to a maximum of six students from their caseloads. If six or fewer students met inclusion criteria, researchers had therapists attempt to recruit each of those students. If more than six students met inclusion criteria, researchers randomly selected six students for therapists to recruit. Recruitment continued until therapists had at least 1 and up to 6 students they would follow for the school year. Complete recruitment procedures are described by Effgen et al. (2016). Researchers obtained IRB approval from the universities and school districts who participated in the study.

Participants

Seventeen PTs provided services to students with DS. All of the PTs were white females with an average age of 43.6 years (SD 10.0, range 27–59 years of age) who worked in SBPT for an average of 8.1 years (SD 5.1, range 1–18 years). Forty-one percent were members of the American Physical Therapy Association and most (70.6%) had not sought additional post-professional education.

There were 46 students with DS with an average age of 6.8 years (SD = 1.74, range 5–11 years). The majority were female and white. Students were categorized into three groups based on the GMFCS: GMFCS I, GMFCS levels II/III, and GMFCS levels IV/V to describe functional mobility. The majority of the students also received speech-language services and occupational therapy at school, and more students spent the majority of their school day in special education classes compared to regular education classrooms. Table 1 includes participant demographics.

Table 1 Demographics of participants and physical therapists

Physical therapists	
Number	17
Mean age in years (SD)	43.6 (10.0)
Sex (%)	
Female	17 (100)
Race (%)	
White	17 (100)
Ethnicity (%)	
Non-Hispanic	17 (100)
Entry-level professional degree	
Bachelor's	10 (58.8)
Master's	3 (17.6)
DPT	4 (23.5)
Highest post-professional degree (%)	
None	12 (70.6%)
PT clinical doctorate	2 (11.8%)
Academic doctorate (PhD, EdD, DSc)	3 (17.6%)
Employment status (%)	
Full-time	9 (52.9)
Part-time	8 (47.1)
Average years practice as a school-based PT (SD)	8.1 (5.1)
APTA member (%)	
Yes	7 (41.2)
No	10 (58.8)
Pediatric certified specialist (%)	
Yes	3 (17.6)
No	14 (82.4)
Students with Down syndrome	
Number	46
Mean age in years (SD)	6.8 (1.7)
Age group (%)	
5–7	28 (60.9)
8–12	18 (39.1)
Sex (%)	
Male	20 (43.5)
Female	25 (54.3)
Not identified	1 (2.2)
Race (%)	
White	38 (82.6)
Black	3 (6.5)
Multi-racial	1 (2.2)
Asian	1 (2.2)
American Indian	1 (2.2)
Other	1 (2.2)
Not identified	1 (2.2)
Ethnicity (%)	
Non-Hispanic	40 (87.0)
Hispanic	5 (10.9)
Not identified	1 (2.2)

Table 1 (continued)

Students with Down syndrome	
Geographic region (%)	
Central (CO, KS, MO, NE, NM, OK)	14 (30.4)
Southeast (FL, KY, NC, VA)	13 (28.3)
Northwest (NV, WA)	11 (23.9)
Northeast (OH, DE, PA, MD)	8 (17.4)
GMFCS groups (%)	
Group 1—Level I	27 (58.7)
Group 2—Levels II/III	17 (37.0)
Group 3—Levels IV/V	2 (4.3)
Other services received (%)	
Speech language therapy	44 (95.7)
Occupational therapy	43 (93.5)
Adapted physical education	22 (47.8)
Classroom typical day (%)	
Special education classroom	22 (47.8)
Regular education classroom	10 (21.7)
Combination	13 (28.3)
Not identified	1 (2.2)
Received clinic-based PT services (%)	6 (13.0)

Measures

School-Physical Therapy Interventions for Pediatrics Data Form (S-PTIP)

The S-PTIP data form was used to document SBPT services (McCoy et al. 2014). PTs documented the minutes they spent working on 14 specific activities and 79 interventions using 5-min time increments. Examples of activities and interventions therapists could choose from are on the S-PTIP form cited below. If therapists addressed activities or interventions not on the form, they could be added. Therapists documented therapy services provided directly with the student (e.g. individual, group, within a school activity) and time spent on behalf of the student (e.g. consultation, collaboration, and documentation), using 5-min increments. Therapists then documented the activity categories used in therapy as pre-functional, sitting/standing/transitions, classroom activity, mobility, physical education (PE)/recreation, self-care, communication, and other. Therapists also documented interventions used during therapy in the following categories of neuromuscular, musculoskeletal, cardiopulmonary, integumentary, orthoses, mobility assistive devices, mobility, positioning, equipment, sensory, educational, assessment, and other interventions. S-PTIP has acceptable face and content validity and intra-rater reliability ($\alpha = 0.95$) (Effgen et al. 2016; McCoy and Linn 2011). The S-PTIP form

is available at <https://www.uky.edu/chs/academic-programs/departments-rehabilitation-sciences/physical-therapy/pt-counts>.

Goal Attainment Scaling (GAS)

GAS is a criterion-referenced outcome measure used to document change in an observable, repeatable, measurable, and time-referenced goal (Kiresuk et al. 2014). GAS commonly uses a five-point scale from -2 to $+2$ with baseline or present level of performance given a value of -2 . The expected outcome is assigned a value of 0 with $+1$ and $+2$ representing outcomes beyond the expected level of progress. A value of -1 indicates less-than-expected progress and we added a score of -3 to indicate regression (Chiarello et al. 2016; King et al. 2000).

GAS is both valid and reliable in children who have motor delays (Steenbeek et al. 2007), and more responsive to functional performance changes than other standardized measures (Steenbeek et al. 2011). Interrater reliability is good to excellent ($r = 0.64\text{--}0.82$) (Steenbeek et al. 2010).

School Function Assessment (SFA)

The SFA is a standardized, criterion-referenced tool that assesses kindergarten through sixth grade students' functional abilities in the educational setting (Coster et al. 1998). Three sections measure a student's *participation*,

task supports (assistance and adaptations), and activity *performance* at school. For this study, the activity performance physical subtests of travel, maintaining and changing positions, manipulation with movement, and recreational movement were assessed. Scoring uses a Likert scale of 1 (does not perform) to 4 (consistent performance) with the *activity performance* section (Coster et al. 1998). Individual item scores were tabulated to determine a total raw score for each SFA subtest. The SFA has high internal consistency values (0.92 to 0.98) for students in special education and test–retest reliability $r > 0.80$ (Coster et al. 1998; Davies et al. 2004).

Gross Motor Function Classification System (GMFCS)

The GMFCS is a 5-level system used to classify the functional mobility and need for assistive devices and caregiver assistance in children with cerebral palsy (CP) (Rosenbaum et al. 2008). Classification is made based on the student's current gross motor function in daily activities with GMFCS level I representing independent ambulation and GMFCS level V representing a student who is dependent on others for all mobility. The GMFCS has evidence of content, construct, and discriminative validity, and inter-rater reliability specifically for students with CP (Bodkin et al. 2003; Ko et al. 2011). Although the GMFCS was developed for children with CP, we used the classification system to identify the functional ability of students as it was the most appropriate option with clear descriptions between levels.

Procedures

During the 2011–2012 school year, researchers recruited SBPTs from across the United States. The PTs completed online training related to research ethics, and the S-PTIP, GAS, and SFA measures. PTs earned an 80% or greater passing score on all written tests related to the measures and following video analysis of students, completed the S-PTIP form with at least 70% agreement with investigators (Effgen et al. 2016).

At the beginning of the 2012–2013 school year, PTs identified each student's GMFCS level, administered the SFA subtests, and converted student IEP goals in the areas of posture/mobility, recreation/fitness, self-care, and academics into GAS format. These areas were selected because motor and adaptive functioning are the focus of most SBPT's interventions and these areas focus on participation of the student during the school day (Effgen et al. 2007, Chiarello et al. 2016). The research team critically and systematically reviewed each submitted goal to verify the goals met criterion for GAS format. Therapists selected goals that had been developed with the IEP team, of which parents' input was imperative. If therapists submitted more than one goal

for review, the research team asked therapists to select one goal as the primary goal, based on which goal was most indicative of student participation in the school day and most addressed by physical therapy services (Chiarello et al. 2016). During the next 20 weeks of the school year, not including holiday and school breaks, PTs completed the S-PTIP form weekly to document SBPT services. Following 20 weeks of intervention, PTs re-administered the SFA subtests and scored the GAS goals.

Data Analysis

Research Electronic Data Capture (REDCap) (Harris et al. 2009) was used for data entry and management and SAS 9.3 (Cary, NC) for statistical analysis. Analysis included descriptive statistics for participants' demographics, S-PTIP, GAS goals, and SFA. To examine the association between minutes of services and minutes in activities to meeting or exceeding GAS goals, logistical regressions analyses were completed and reported using the Wald Chi squared test as well as the associated p values. To explore changes in SFA scores ANOVA longitudinal mixed models methodology were used for the analysis. Age, gender, and GMFCS levels were examined for effect modification or confounding relationships. With evidence of effect modification, stratified analysis was used, adjusting for confounders. All analyses were planned a priori. To account for multiple comparisons we set the alpha level at 0.01. To assist with analysis we grouped GAS goals and minutes of therapy services as explained in the next two sections.

GAS Goals

For analysis we dichotomized students with DS into two groups: those who met or exceeded their primary GAS goal (GAS = 0, 1, 2) and those who did not meet their primary GAS goal (GAS = -3, -2, -1) and performed logistic regression using sitting/standing/transitions, mobility, and PE/recreation activities. We examined the number of minutes of direct SBPT each student received during the 20 weeks to determine if the total number of minutes of therapy were associated with the number of met or exceeded GAS goals.

Minutes in Therapy Services

We divided the student participants into groups of similar size by the amount of time they participated in therapy sessions to make the most accurate comparison between groups. Within the sitting/standing/transition activities, we divided students into two groups, those students who spent < 25 min ($n = 25$) and those who spent > 25 min ($n = 21$). We divided the mobility activity into three groups; 0–40 min ($n = 17$),

41–95 min ($n = 14$), and > 95 min ($n = 15$), and the PE/recreation activity into three groups; 0–115 min ($n = 17$), 116–290 min ($n = 14$), and > 290 min ($n = 15$). To allow for the number of students in each group to be similar for analysis, we used tertiles to divide students into three groups to categorize total time among mobility and PE/recreation activities.

Results

On average, students with DS received 24.0 min/week (SD 13.9) of total direct therapy services and 11.6 min/week (SD 6.1) of services on behalf of the student, for a total of 35.6 min/week (SD 17.9) of SBPT. Table 2 includes a complete summary of SBPT services. The most common

activities were PE/recreation (11.2 min/week, SD 10.8), mobility (4.5 min/week, SD 4.7), and sitting/standing/transition (3.2 min/week, SD 6.2) (Table 3). Interventions for students with DS focused on neuromuscular (29.5 counts/student/20 weeks, SD 17.7), mobility (14.1 counts/student/20 weeks, SD 14.4), and musculoskeletal (11.5 counts/student/20 weeks, SD 7.1) (Table 4).

The student's primary GAS goals were in the areas of posture/mobility (45.6%) or recreation (41.3%). Students met or exceeded 66.7% of the posture and mobility goals and 73.7% of the recreation goals. Overall, 32 (69.5%) students individually met or exceeded their primary outcome GAS goal. Students mean SFA subtest scores increased between 2.2 and 3.7 points following 20 weeks of SBPT. Table 5 includes the descriptive of the SFA subtest raw score changes from pre-test to post-test for students with DS.

Table 2 Direct services and services on behalf of the student with Down syndrome

Characteristic of service	Average total minutes over 20 weeks (SD)	Average minutes per week(SD)	99% Confidence interval of average weekly minutes	Range
Total direct services to the student	480.1 (278.0)	24.0 (13.9)	[18.7, 29.3]	80/1685
Total services on behalf of the student	232.8 (122.1)	11.6 (6.1)	[9.8, 13.4]	60/600
Individual	329.1 (292.0)	16.4 (14.6)	[10.9, 21.9]	0/1585
Group	147.3 (201.4) ^a	7.4 (10.1)	[3.6, 11.2]	0/770
Non-special education	57.3 (120.9)	2.9 (6.0)	[0.6, 5.2]	0/565
Special education	188.0 (262.1)	9.4 (13.1)	[4.4, 14.4]	0/1365
With no other students	236.3 (221.4) ^a	11.8 (11.1)	[7.6, 16.0]	0/1065
Within a school activity	150.6 (234.9)	7.5 (11.7)	[3.1, 11.9]	0/1485
Separate from school activity	316.7 (238.8) ^a	15.8 (11.9)	[11.3, 20.3]	0/1125
Co-treatment	68.1 (97.6) ^b	3.4 (4.9)	[1.5, 5.3]	0/320
Consultation	92.9 (81.9)	4.6 (4.1)	[3.0, 6.2]	0/390
In-service	0 (0)	0 (0)	0	0/0
Curriculum development	4.3 (25.1)	0.2 (1.2)	[0, 0.6]	0/170
Documentation	135.5 (65.8) ^a	6.8 (3.3)	[5.8, 7.8]	50/380

^aRounding differences

^bNot included in sum of direct services

Table 3 Duration of activities in school-based physical therapy

Activity	Average minutes over 20 weeks (SD)	Average minutes per week (SD)	99% Confidence interval for average weekly minutes	Range
PE/recreation	224.4 (217.1)	11.2 (10.8)	[7.1, 15.3]	0–1140
Mobility	91.0 (93.7)	4.5 (4.7)	[2.7, 6.3]	0–455
Sitting/standing/transitions	64.0 (125.0)	3.2 (6.2)	[0.8, 5.6]	0–755
Pre-functional activities	42.2 (66.3)	2.1 (3.3)	[0.8, 3.4]	0–265
Other	26.6 (56.3)	1.3 (2.8)	[0.2, 2.4]	0–345
Self-care	20.9 (81.7)	1.0 (4.1)	[0, 2.6]	0–475
Classroom activity	10.6 (22.5)	0.5 (1.1)	[0.1, 0.9]	0–100
Communication	0.3 (1.2)	0.01 (0.06)	[0, 0.03]	0–5

Table 4 Intervention counts during 20 weeks of school-based physical therapy

Intervention	Mean number of counts over 20 weeks (SD)	99% Confidence interval for mean number counts over 20 weeks	Range
Neuromuscular	29.5 (17.7)	[22.8, 36.2]	3–79
Mobility	14.1 (14.4)	[8.6, 19.6]	0–57
Musculoskeletal	11.5 (7.1)	[8.8, 14.2]	0–28
Other	5.8 (8.3)	[2.6, 9.0]	0–35
Educational	4.3 (7.4)	[1.5, 7.1]	0–36
Assessment	3.3 (4.6)	[1.6, 5.0]	0–17
Orthoses	2.3 (5.0)	[0.4, 4.2]	0–20
Cardiopulmonary	1.6 (2.6)	[0.6, 2.6]	0–10
Sensory	1.5 (4.7)	[0.0, 3.3]	0–30
Mobility assistive	1.2 (3.5)	[0.0, 2.5]	0–18
Equipment	0.4 (0.9)	[0.1, 0.7]	0–4
Integumentary	0.3 (1.5)	[0, 0.9]	0–10
Positioning	0.3 (0.9)	[0.0, 0.6]	0–5

Table 5 SFA raw scores before and after 20 weeks of school-based physical therapy

Subtest	Mean score Pre-test (SD)	Range of pre-test scores	Mean score Post-test (SD)	Point score change	Range of post-test scores
Travel	61.7 (13.1)	19/76	65.3 (12.7)	+3.6	20/76
Maintaining and changing position	42.1 (7.0)	16/48	44.3 (5.4)	+2.2	21/48
Manipulation with movement	48.4 (12.5)	17/64	52.7 (11.8)	+4.3	17/64
Recreational movement	27.6 (8.7)	11/41	31.3 (9.8)	+3.7	11/44

Association Between Minutes of Services and Minutes in Activities to GAS Goals

No main effects were significant so no confounding variables were identified. There was no association between minutes of SBPT and increased proportion of students attaining or exceeding primary GAS goals (Wald $\chi^2=0.45$, $p=0.50$). Nor was there an association between the number of minutes spent in the top three activity areas and attaining or exceeding the GAS goal: PE/recreation (Wald $\chi^2=2.3$, $p=0.32$), mobility (Wald $\chi^2=2.0$, $p=0.36$), or sitting/standing/transition (Wald $\chi^2=0.48$, $p=0.49$). Students did not meet their GAS goals more often based on the total amount of time PTs spent on behalf of the student (Wald $\chi^2=1.1$, $p=0.28$), nor when the amount of time spent on behalf of the student was broken up into consultation (Wald $\chi^2=0.45$, $p=0.50$) and documentation (Wald $\chi^2=0.88$, $p=0.35$).

Change in SFA Subtest Scores

There was no evidence of effect modifiers nor confounders in the SFA longitudinal model (GMFCS: $F=1.62$, $p=0.21$; age: $F=0.04$, $p=0.84$; gender: $F=0.08$, $p=0.78$), the maintaining and changing positions SFA longitudinal model (GMFCS: $F=4.10$, $p=0.02$; age: $F=0.84$, $p=0.36$;

gender: $F=4.12$, $p=0.05$), or the manipulation with movement SFA longitudinal model (GMFCS: $F=1.83$, $p=0.17$; age: $F=1.37$, $p=0.23$; gender: $F=0.64$, $p=0.84$). However, GMFCS level was a significant confounder in the travel model ($F=30.76$, $p<0.001$), the maintaining and changing positions model ($F=55.02$, $p<0.001$), and the manipulation with movement model ($F=22.96$, $p<0.001$). Following adjustment for the GMFCS confounder, students scored 3.7 points higher (99% CI 1.7, 5.6) in the travel subtest, 2.2 points higher (99% CI 1.1, 3.3) in the maintaining and changing positions subtest, and 4.3 points higher (99% CI 2.2, 6.4) in the manipulation with movement subtest, following 20 weeks of SBPT compared to baseline SFA score ($p<0.001$).

For the recreational movement SFA subtest there was evidence that GMFCS level was an effect modifier in the relationship between baseline and 20-week recreational movement SFA subtest scores ($F=7.02$, $p=0.002$). Stratified analysis was used at each GMFCS level. For students in GMFCS level I, neither gender nor age were significant effect modifiers in the relationship between pre and post recreational movement scores (gender: $F=0.001$, $p=0.97$; age: $F=0.001$, $p=0.96$) and the students recreational movement SFA scores increased 5.3 points (99% CI 3.2, 7.3) compared to baseline ($p<0.001$). For students at GMFCS levels II/III,

neither gender nor age were significant effect modifiers in the relationship between pre and post recreational movement subtest scores (gender: $F=0.92$, $p=0.35$; age: $F=0.04$, $p=0.85$), however students recreational movement subtest scores did not significantly change ($F=5.53$, $p=0.03$). No statistical analysis was performed for students in GMFCS levels IV/V, because there were only two students.

Discussion

This study was the first to describe SBPT services for students with DS and to examine their response to SBPT services, using functional outcome measures. Students with DS received both direct and on-behalf of the student SBPT services a few minutes less on average than the entire sample of students in the PT COUNTS study (26.8 min/week direct and 13.2 min/week on behalf) (Jeffries et al. 2018). Most direct SBPT took place apart from classroom peers and PTs spent almost twice as many minutes addressing skills separate from a school activity than minutes spent addressing skills within a school activity. This finding is counter to current evidence that supports integrating services with peers or students demonstrating more advanced gross motor skills, as these students model how to correctly perform the skill (Kaminker et al. 2004; Thomason and Wilmarth 2015). However, our sample was young suggesting skills may still be being taught to younger students with DS in the school setting. School-based PTs should consider the importance of integrating SBPT for students with DS into typical school activities with peers in an effort to facilitate skill retention, generalization, and skill mastery (Winders 2001).

In “time on behalf of the student” SBPT services, PTs spent almost 59% of their time documenting services and almost 40% of their time consulting with school staff. Documentation typically supports progress monitoring, provides details of SBPT sessions, and can include letters of medical necessity for equipment to third party payers and physicians (Effgen and McEwen 2008). Documentation also helps PTs plan for future visits and provides specificity of services so that other PTs could implement services. Collaboration and in-service trainings are two integral ways PTs can support school staff and families once students are ready to generalize the skills they have attained (Effgen et al. 2007; Thomason and Wilmarth 2015). Our study suggested that “time on behalf of the student” may be an important component of SBPT for students with DS, and should be considered as part of the workload.

Many students received a combination of individual and group therapy. For school-aged students, group therapy can be beneficial for children with CP (Blundell et al. 2003) and developmental coordination disorder (Peters and Wright 1999). However, for children with DS the results of

group therapy is limited to one study of infants and toddlers (LaForme-Fiss et al. 2009), and needs to be explored for school-age students with DS. Generally, students with DS enjoy playing with other students and often mimic actions of other students, which may enhance the effectiveness of group therapy for students with DS.

PTs spent a majority of time on PE/recreation activities, typically in isolated settings. This seems contradictory, but we did not investigate what level of skills development (acquisition, fluency, or generalization) the students were working on. As PE/recreation activities should be generalizable into school and community activities, we encourage PTs to work on these activities within the PE classes, on the playground with other students, and in the community. As students with DS age, they become more sedentary and participate less in moderate to vigorous physical activity (Esposito et al. 2012). School-based PTs play an important role in prevention and educating the student, IEP team, and family about the risks associated with sedentary lifestyles and should facilitate the student’s engagement in school and community activities that support movement.

Neuromuscular, mobility, and musculoskeletal interventions were the most common interventions and similar to the PT COUNTS study. These findings were not surprising since children with DS often have balance problems (Wang and Ju 2002), hypotonia (Galli et al. 2008), and delayed gross motor skills (Malak et al. 2013). However, therapists rarely implemented cardiopulmonary interventions although individuals with DS can have lifelong cardiopulmonary system impairments that increase with age (Barnhart and Connolly 2007). Beyond the three common interventions, PTs should consider interventions that support the cardiopulmonary system for students with DS to support endurance requirements for full participation in school and community activities (Effgen et al. 2007).

Similar to another study of students in school-based programs (Stuberg and DeJong 2007), the majority of students with DS met or exceeded their GAS goal. The use of GAS can demonstrate clinically significant changes for students with disabilities (Chiarello et al. 2016; McConlogue and Quinn 2009). SBPTs selected primary goals predominantly in the areas of posture/mobility, recreation/fitness, and self-care (91.3%), and to a much lesser extent, academics (8.7%). This may have been due to the PT focusing on their own strengths, and not feeling as comfortable focusing on academics, or realizing teachers addressed academic goals. Selecting goals during an IEP meeting, which includes the entire IEP team, parents, and students, if appropriate, may lead to improved outcomes on measures such as GAS (Chiarello et al. 2016).

On the SFA, students with DS demonstrated significant increases in raw scores for travel, maintaining and changing positions, and manipulation with movement subtests.

For students with greater functional mobility, thus a higher GMFCS level, recreation subtest raw scores increased following 20 weeks of SBPT but those with less functional mobility did not have significant changes. When using raw scores, PTs should examine specific test items to consider whether this significant change was clinically relevant. For example, a student who improves from a “2” (partial performance) during the pretest on the item “can do two or more of the following: running, hopping, skipping, or jumping” to a “4” (consistent performance) on the same item during the post-test would, more than likely, demonstrate clinically important change in function. These students are more likely to show improved participation in recreation activities with peers if they can consistently perform several gross motor ambulation skills at the same level as typically developing peers.

Strengths and Limitations

This is the first study to examine SBPT services for students with DS, however we recognize the sample size was small, heterogeneous, and only included young students; therefore, causal relationships could not be established and results and generalizability of results must be studied with caution. All of the PTs were Caucasian females over 40 years of age, similar to information provided to us by our national professional organization, the American Physical Therapy Association (S. Miller, E-mail Communication, May 16, 2019). This limitation does not provide how therapists of other genders or races might provide school-based services. Another limitation is we used the GMFCS as a proxy for gross motor function in children with DS when in fact it was developed for children with CP. The GMFCS was used to group all participants in the PT COUNTS study, regardless of diagnosis, into clearly defined levels, based on functional mobility. The GMFCS provided a clear means of grouping children by functional abilities which can influence the activities and interventions SBPTs implement during therapy services.

Future Research

For school-based PTs to make evidence-based decisions regarding services for students with DS, future investigation is needed. PT’s choice of service location and what level of skill development (acquisition, fluency, or generalization) they are addressing should be explored to determine how location and level of skills development is related. For skill acquisition, services need to be individualized and often therapists decide to work in isolation away from other students and usually in a therapy room; however, this study did not investigate the PT’s reasoning for service location. Further investigation regarding which

activities and interventions best support achievement outcomes and where students with DS receive PT services should be replicated with a larger, heterogeneous sample size. PTs should however reflect on the location of SBPT as best practice currently guides therapists to provide services during typical school day activities with peers to support generalization of skills. Including school systems in larger, urban areas in research studies may help increase the number of heterogeneous participants in nationwide studies to obtain a more accurate, inclusive look at SBPT, and how PTs address activities and perform interventions with students with DS in the educational setting.

Conclusion

This study was the first nationwide study to examine students with DS and describe SBPT services and functional outcomes. A description of the amount of therapy, specific activities, and interventions used in SBPT provided a glimpse into the SBPT services students with DS receive. Students with DS achieved higher SFA post-test scores and most students met or exceeded their primary GAS goal. This study provided initial observational data about physical therapy services for students with DS who received school-based services.

Acknowledgments This article is a product of the PT COUNTS study which was supported by the Institutes of Education Sciences, US Department of Education, Grant R324A110204.

Author Contributions GEN participated in developing the idea for the research article, conducted data analysis, writing the article from doctoral thesis for DSc degree, revision of edits, and proofing the final manuscript. SKE participated in developing the idea for the research article, conducted data collection for the PT COUNTS study, writing, providing additional edits during revision, and proofing subsequent submissions. SA participated in writing, providing additional edits during revision, and proofing subsequent submissions. JB participated in data analysis, and provided additional edits during revision. LMJ participated in developing the idea for the research article, conducted data collection in the PT COUNTS study, participated in data analysis, writing, providing additional edits during revision process, and proofing the final manuscript.

Funding This study was supported by the Institutes of Education Sciences, US Department of Education, Grant Number R324A110204.

Compliance with Ethical Standards

Conflict of interest Glen E. Neal, MPT, DSc, PCS declares that he has no conflict of interest. Susan K. Effgen, PT, PhD, FAPTA declares that she has no conflict of interest. Lynn M. Jeffries, PT, DPT, PhD, PCS declares that she has no conflict of interest. Sandra Arnold, PT, PhD declares that she has no conflict of interest. Jonathan Baldwin, MS, CNMT, RT(CT) declares that he has no conflict of interest.

Ethical Approval All procedures performed in studies involving human participants were in accordance with ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards.

Informed Consent Informed consent was obtained from all individual participants included in the study.

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