

Marquette University

**e-Publications@Marquette**

---

Exercise Science Faculty Research and  
Publications

Exercise Science, Department of

---

12-2019

## **Feasibility and Acceptability of a Self-Report Activity Diary in Families of Children with and Without Special Needs**

Bethany Forseth

Paula Papanek

Linda Bandini

Dale A. Schoeller

Andrea Moosreiner

*See next page for additional authors*

Follow this and additional works at: [https://epublications.marquette.edu/exsci\\_fac](https://epublications.marquette.edu/exsci_fac)

---

---

**Authors**

Bethany Forseth, Paula Papanek, Linda Bandini, Dale A. Schoeller, Andrea Moosreiner, Kathleen J. Sawing, Kimberley Zvara, Michael Fendrich, and Michele Polfuss

---

Marquette University

**e-Publications@Marquette**

***Exercise Sciences Faculty Research and Publications/College of Health Sciences***

***This paper is NOT THE PUBLISHED VERSION.***

Access the published version via the link in the citation below.

*Comprehensive Child & Adolescent Nursing*, Vol. 42, No. 4 (December 2019): 293-303. [DOI](#). This article is © Taylor & Francis Group and permission has been granted for this version to appear in [e-Publications@Marquette](#). Taylor & Francis Group does not grant permission for this article to be further copied/distributed or hosted elsewhere without the express permission from Taylor & Francis Group.

# Feasibility and Acceptability of a Self-Report Activity Diary in Families of Children with and Without Special Needs

Bethany Forseth

College of Health Sciences, University of Wisconsin, Milwaukee, WI

Paula E. Papanek

Physical Therapy, Marquette University, Milwaukee, WI,

Linda Bandini

Department of Pediatrics, Eunice Kennedy Shriver Center/UMASS Medical School, Worcester, MA  
College of Health and Rehabilitation Sciences, Boston University, Boston, MA

Dale Schoeller

Department of Nutritional Sciences, University of Wisconsin, Madison, WI

Andrea Moosreiner

Clinical and Translational Science Institute, Medical College of Wisconsin, Milwaukee, WI

## **Kathleen J. Sawing**

College of Nursing, University of Wisconsin-Milwaukee, Milwaukee, WI

## **Kimberley Zvara**

Physical Medicine and Rehabilitation, Children's Hospital of Wisconsin, Milwaukee, WI  
Medical College of Wisconsin, Milwaukee, WI

## **Michael Fendrich**

University of Connecticut School of Social Work, Hartford, CT

## **Michele Polfuss**

Department of Nursing Research, Children's Hospital of Wisconsin, Milwaukee, WI  
College of Nursing, University of Wisconsin-Milwaukee, Milwaukee, WI

## **Abstract**

This study was conducted to examine the feasibility and acceptability of a self-report activity diary completed by parents and older children to assess the child's daily activity in children with and without special needs. The study included 36 child/parent dyads stratified by child age and diagnosis. Parents (n = 36) and children  $\geq 13$  years (n = 12) were asked to report on the child's daily activity using an activity diary. Feasibility was determined based on successfully returned diaries and acceptability via post-study interview. Activity diaries were submitted by 94% of the parents and 100% of the children, with 83% and 80%, respectively, successfully completed. Comments provided post-study regarding the diaries were primarily on the format and were generally negative. The activity diary was feasible to use, but not well accepted within our sample of children with and without special needs or their parents. Further research is needed to create valid physical activity assessment measures that are population specific for individuals with special needs.

## **Keywords**

Spina bifida; Down syndrome; parent; physical activity; subjective measurement

## **Introduction**

Physical activity is an essential component of health maintenance and promotion. This is especially important in children with special needs, specifically spina bifida and Down syndrome, because they have a higher prevalence of obesity and risk of developing chronic health issues later in life as compared to their typically developing peers (Dosa, Foley, Eckrich, Woodall-Ruff, & Liptak, [ 5]; Ogden, Carroll, Kit, & Flegal, [12]; Physical Activity Guidelines Advisory Committee, [13]; Van Riper & Cohen, [19]). To best define relationships between physical activity and health outcomes (e.g. overweight/obesity, type 2 diabetes, and cardiovascular disease) valid and reliable methods of measuring physical activity are essential but are currently limited in options for children with special needs.

Physical activity can be assessed through both subjective and objective methods. Subjective methods for assessing physical activity include self-report data through questionnaires or diaries that can include characteristics of physical activity, such as mode, frequency, duration, and/or total amount of activity. These methods are often used because they are cost effective, feasible to complete and can be administered to a large sample (Corder, Crespo, van Sluijs, Lopez, & Elder, [ 4]; Elliott, Baxter, Davies, & Truby, [ 7]; Elliott, Davidson, Davies, & Truby, [ 8]; Thorn, DeLellis, Chandler, & Boyd, [17]; Warner et al., [21]). A potential drawback of subjective methods are the mixed reports on their accuracy, which may be related to social desirability bias and

the potential of high burden for the participant (Dowda, Pate, Sallis, Freedson, & Taylor, [ 6]; Haskell, [ 9]; Rebholz et al., [15]; Teder et al., [16]; Tucker et al., [18]).

When using subjective methods to assess physical activity in young children, parents are often used as a proxy-reporter in completing the self-report tool (Barr-Anderson, Robinson-O'Brien, Haines, Hannan, & Neumark-Sztainer, [ 2]; Rebholz et al., [15]). As children develop and become more independent, their ability to report their own activity would be expected to improve due to increasing cognitive skills that facilitate comprehension of the task. Furthermore, the request for their input on their daily activity is necessary as their time spent not directly supervised by parents usually increases. Parents of children with special needs are likely to be more involved in their child's day-to-day lives than parents of typically developing children due to diagnosis-related responsibilities (McCann, Bull, & Winzenberg, [11]). Depending on the diagnosis, the parent's increased involvement may continue through the child's adolescent years. Therefore, it would seem plausible that parents of children with special needs could provide credible reports of physical activity from early childhood through adolescence.

Currently there is no information on optimal strategies to assess physical activity in children with special needs. Thus, evaluating a cost-effective method of activity assessment for this at-risk population is important. The purpose of this paper was to examine the implementation of a self-report activity diary (previously used by parents of children who were typically developing) in a sample of parents and children 13 years of age and older with and without special needs. The aims of this study were to: 1) examine the feasibility of successfully completing the activity diaries by parents and older children; 2) examine the acceptability of using this diary through family responses provided during a post-study phone interview. Children without special needs and their parents were deliberately included to provide additional context of how the tool was perceived and to highlight any potential variations that may emerge for the children with special needs and their parents. Finally, lessons learned related to the implementation and subsequent challenges associated with the use of and issues surrounding the lack of validated physical activity measures for children with special needs will be discussed.

## Materials and methods

### Design

This descriptive analysis was part of a cross-sectional pilot study that examined the measurement of energy expenditure in children with and without special needs (Polfuss et al., [14]). The study was conducted within a Midwestern Pediatric Hospital's Translational Research Unit (PTRU). Study approval was obtained by the hospital's Institutional Review Board. Prior to testing, each participant (child and parent) signed an informed assent and/or consent.

### Participants

A sample of 36 child and parent dyads were recruited through local hospital clinics and community organizations. Recruitment was stratified by child age, diagnosis and ambulatory status (Down syndrome, spina bifida [ambulatory], spina bifida [primary uses a wheelchair], and a control group without chronic illness). A questionnaire that included information on child age (in years) and parent education level was completed by parents at the time of data collection. Full inclusion criteria have been previously reported (Polfuss et al., [14]).

### Measures

#### *Self-report activity diary*

A previously published self-report activity diary, developed for assessing activity in children who were typically developing, was used to collect activity information (Bringolf-Isler et al., [ 3]). This diary listed 20 common daily activities (e.g. school lessons, recess, watching TV, reading, vigorous games, etc.) categorized into five broad

categories (general, school, leisure time, travel, and special). The diary divided the 24-hour day into 15-minute increments (Bringolf-Isler et al., [ 3]). To accommodate all forms of mobility, this diary was modified to include an option of 'by wheelchair' under the 'travel' category in addition to the standard options of "by foot, by car, by bicycle." The diaries were provided to all parents (n = 36) and children  $\geq 13$  years (n = 10) with the request that the child's physical activity was recorded on six days (four weekdays and two weekend days) of their choice over a two-week period. When parents were not directly observing their child (e.g. when the child was at school, sports or daycare), the parents were asked to use their best judgement for selecting the activity that the child was engaging in during that time. Predetermined successful completion of the diary was defined as diaries that included  $\geq 4$  diary days that included at least one weekend day and accounted for  $\geq 80\%$  of each reported day.

### *Post-study interview*

As a part of the larger study, a five question post-study phone interview was conducted with the families. The final two questions were: "On a scale of 1–10 with 1 being very easy and 10 being very difficult, how would you rate your family's participation in this study?" and "Do you or your child have any suggestions on how to improve the study?" While these two questions did not specifically speak to the self-report diaries, they were included in this analysis as responses from families primarily focused on the diaries.

### *Data analysis*

Descriptive statistics assessed sample characteristics. Percentages for feasibility were calculated based on the number of participants who returned and successfully completed the diaries. The mean from the post-study question, addressing the ease of participating in the study on a 1–10 scale, was calculated and themes based on responses in the open-ended question was created to categorize comments.

## Results

Complete demographic results have been previously reported (Polfuss et al., [14]). The majority of parents in this study participated in higher education, with 56% completing at least one college degree or a formalized training program. An additional 28% attended college or a formalized training program, 14% completed high school, and 2% attended high school.

Activity diaries were submitted by 34 of the 36 parents (94%); however only 30 (83%) of the submitted diaries met the criteria of successful completion (defined above) (Table 1). Child diagnoses of the six parents who did not submit or successfully complete the diaries, included one child with Down syndrome, two children with spina bifida who were ambulatory, and three children with spina bifida who used a wheelchair for mobility. Diaries were only provided to 10 of the possible 12 children in the 13–18-year-old age group due to parent concerns that their child, both diagnosed with Down syndrome, would not be able to complete the diary. All ten of the children who were provided with diaries submitted them at the end of the study (100%), and eight of those children had successful completion of the diaries (80%) (Table 1). The two children who submitted the diaries but did not meet the criteria for successful completion were diagnosed with spina bifida and used a wheelchair for ambulation (Table 1).

Table 1. Self-report diary results.

	Down Syndrome	Spina Bifida Ambulatory	Spina Bifida Wheelchair	No Chronic Illness
Parent Diaries Submitted (n)	9	8	8	9
Parent Diaries Successfully Completed (n)	8	7	6	9
Child Diaries Submitted (n)	1	3	3	3
Child Diaries Successfully Completed (n)	1	3	1	3

1 Note. (n) = sample size

The post-study questionnaire was answered primarily by mothers. Examining the ease of study participation within the larger study the average parent response for the difficulty of the study, on a 1–10 scale was 2.5, indicating that the study was 'fairly easy' to complete as a whole. Nineteen of the 36 families (53%) provided responses to the open-ended question, asking how to improve the study, with the majority of comments addressing the diaries. If a parent included multiple topics within their response, topics were separated and analyzed separately. Categories of themes were created based on responses about the diaries. Most of the diary-related comments were specific to aspects of the diary's format. Additionally, there were general responses of like or dislike for the diary. Respective themes were defined based on these comments (Table 2). Ultimately, four participants identified the study as easy and that no improvements were recommended. Positive comments about the diary were provided from two parents; one with a child diagnosed with Down syndrome and one with spina bifida. In contrast to these positive comments, 12 (33%) of the 36 parents commented on specific ways to improve the diaries and/or concerns in completion of the diary. These comments came from families of children in all diagnosis subgroups, including children with and without special needs. The themes and comments specific to the activity diaries are provided in Table 2.

Table 2. Themes and comments about diaries from parents.

Theme	Number of Comments on Theme	Specific Quotes
Recommending including more categories of activities	6	"...some things were not on [the diary] like grooming and getting dressed."
Small spacing of the diary and that it was hard to see	5	"...[diaries] were small and hard to read..." "[diary] was tedious with the 15-minute increments..."
Study as a whole (including the diary) was easy	4	"[study was] straight forward and easy to follow."
Recommending online or alternative format options	2	"...could this be done online?"
Concern about not always being around child	3	"Not comfortable with the activity logs, because [parent] did not see [child] much."
General dislike of the diary	2	"[diaries] were stressful...we are a busy family."

## Discussion

Findings and lessons learned from this study can be used as the foundation for future work in the assessment of physical activity in populations with special needs. The completion of the self-reported diaries was found to be feasible by parents and older children with and without special needs. However, the ability of a child to complete the diary varies among children with special needs as the child's capabilities can vary individually. When working with families, parents are often the best resource to understand their child's capabilities, therefore parent input is commonly included when tasks are requested of the child. In this study, parents of two children with Down syndrome, who were eligible to complete the diaries, expressed concern regarding their child's ability to successfully perform this task. It is also noted that two children who were diagnosed with spina bifida did submit diaries but failed to meet the criteria needed to be included in the analysis. Child participation in research is important and should be encouraged, however, a child's ability to accurately self-report information should be considered on an individualized basis. Therefore, when assessing physical activity in children with special needs, including both the parent and child's assessment may be beneficial.

Comments about the diaries, primarily shared by mothers, were generally negative with specific concerns related to the layout of the diary and the need for additional categories of activities (e.g. grooming or getting dressed). The majority of the comments requesting categories to account for grooming or getting dressed were

from parents of children with spina bifida. This may be due to the extra time that is needed for these activities when the child has a physical disability, thus warranting specific time blocks for these activities within a self-report diary. It was suggested that the tool be made available online or in an easier-to-read format. Due to the concerns and negative responses regarding the diary, it was determined to be unacceptable in its current format. This diary was chosen partially because of its formatting (i.e. time split into 15-minute increments with a checkbox format), however, the formatting was a specific dislike for some families. Based on post-study comments, it is recommended that future studies obtain the input regarding the format of the instrument (e.g. online vs. paper and layout, font and spacing) from a pilot study or representatives of the study sample (e.g. families of children with special needs). These initial steps may increase the acceptability of an instrument and the ability to effectively measure the intervention (Vandelanotte & Bourdeaudhuij, [20]; Weinreich, [22]). This is valuable because lack of acceptability for an instrument, such as this diary, may result in decreased utilization, due to being viewed tedious or burdensome, and subsequently impact the feasibility of a tool.

When choosing tools to use within a study, it is important to select an instrument that is valid within the population of the study. Unfortunately, to the authors' knowledge, there are no validated tools to assess physical activity of children with special needs. Validating physical activity tools in this population is challenging due to potential variations in physiologic responses (e.g. energy expenditure) and body movement. For example, to test the validity of a self-reported physical activity diary focused on time in different activities, each included activity would need to be quantified by the time spent in the activity and an equivalent intensity metric (e.g. metabolic equivalents [METs]) to produce a standardized outcome (e.g. MET.Minutes, MET.Hours, or calories). The outcome measure would then be compared to a valid and reliable criterion measure. If the criterion measure used the same units that the diary was converted to then criterion-related or convergent validity could be tested (Welk, [23]). If the criterion measured a similar variable but different units (e.g. using accelerometer counts compared to the diary metrics) concurrent validity could be tested (Welk, [23]). However, there are no physical activity intensity related metrics and/or equations validated for children with spina bifida or Down syndrome which would enable a comparison of the diary data to an objective measure.

The validation of this diary and the ability to convert activities into measurable units is important because it would allow for the activity to be quantified. Quantifying activity performed would allow for comparisons to other research studies, performed in both children with and without special needs, allowing for a better understanding of the physical activity achieved by participants throughout the day. Additionally, the ability to validate the physical activity performed in the diaries has greater implications because there is limited information on energy expenditure during physical activity in children with spina bifida or Down syndrome. There have been documented differences in total energy expenditure in children with Down syndrome and spina bifida compared to their typically developing peers (Polfuss et al., [14]). These differences are potentially due to lower resting metabolic rates (Bandini, Schoeller, Fukagawa, Wykes, & Dietz, [1]; Hong, [10]; Polfuss et al., [14]), but physical activity energy expenditure may also be impacted. Therefore, self-report measures and metrics/equations based on typically developing populations should not be used in children with special needs because this would introduce bias and lead to questionable or unreliable results due to differences in energy expenditures and other possible physiologic variations. The lack of research on physical activity assessment in children with special needs leaves a gap in knowledge, limits implementation of interventions, creates barriers to weight management, and limits the ability to compare research findings across populations. These consequences therefore warrant the development and validation of a population specific physical activity tool.

There are challenges and concerns that limit the findings of this study. First, the small sample size is a limitation to the findings. Also, the post-study interview, while it provided information on responses to the diaries, did not include questions specific to the diary. It was during the open-ended question that comments were stated about the diary. The comments specifically about the diary were unexpected. In hindsight, the diary should have been

explored with specific diary-related post-study questions for further understanding of its use. Another limitation relates to the lack of validated physical activity diaries for populations with special needs, thus, limiting the analysis and applicability of the data. Future studies should work to either validate currently used metrics/equations in this population or develop new equations specific to individuals with special needs. Additionally, it would be beneficial for future studies of children to incorporate reports from other individuals involved with the child's daily routine (e.g. school personnel). These added reporters can complement the child and parent reports during times when parents are not present.

Despite limitations, strengths of the present study include the use of the activity diary in an understudied population, which provided a cost-effective tool that used 15-minute increments to assess the child's activity. Although this activity diary in its current format is not recommended for use in future studies, the 15-minute intervals or shorter time increments would be encouraged. Although one parent found the 15-minute intervals as tedious (Table 2), the benefit of these shorter time intervals allows for more specific timing and context of activities participated in by children. To decrease potential frustrations and accurately portray time spent in the activity, participants could also have the option to report start and end times of each activity the child engaged in during the day. Additionally, this diary was feasible for both parents and older children, despite the lack of acceptability in its present format.

## Conclusion

Having the ability to assess a child's activity level is important when working to prevent or manage weight issues and promote fitness and metabolic health. This is particularly relevant in children with special needs who are at a higher risk for overweight and obesity. Parents and older children were able to complete a self-reported activity diary on the child's activity. However, this activity diary, in its current layout, was not well-accepted by parents in this study primarily due to diary formatting. As self-report diaries are cost-effective and relatively easy to use, they are an appealing method to assess activity. Until metrics/equations are available for children with special needs, findings will need to be interpreted with caution and validation cannot be performed. This study adds to the literature by highlighting the need for the development of a validated tool that assesses physical activity and the potential for biased results reported in this unique population. Additional research should be conducted to understand how best to perform physical activity assessment in this vulnerable population.

## Acknowledgments

The research team would like to thank the staff at the Pediatric Translational Research Unit for helping in the data collection and the families for participating in this research!

## Conflicts of Interest

All authors have no financial or non-financial conflicts of interest to report.

## References

- Bandini, L., Schoeller, D., Fukagawa, N., Wykes, L., & Dietz, W. (1991). Body composition and energy expenditure in adolescents with cerebral palsy or myelodysplasia. *Pediatric Research*, 29 (1), 70 – 77. doi: 10.1203/00006450-199101000-00014
- Barr-Anderson, D., Robinson-O'Brien, R., Haines, J., Hannan, P., & Neumark-Sztainer, D. (2010). Parental report vs. child perception of familial support: Which is more associated with child physical activity and television use? *Journal of Physical Activity and Health*, 7 (3), 364 – 368.
- Bringolf-Isler, B., Grize, L., Mäder, U., Ruch, N., Sennhauser, F., & Braun-Fahrländer, C. (2009). Assessment of intensity, prevalence and duration of everyday activities in Swiss school children: A cross-sectional

- analysis of accelerometer and diary data. *International Journal of Behavioral Nutrition and Physical Activity*, 6 (1), 1 – 10. doi: 10.1186/1479-5868-6-50
- Corder, K., Crespo, N. C., van Sluijs, E. M. F., Lopez, N. V., & Elder, J. P. (2012). Parent awareness of young children's physical activity. *Preventive Medicine*, 55, 201 – 205. doi: 10.1016/j.ypmed.2012.06.021
- Dosa, N., Foley, J., Eckrich, M., Woodall-Ruff, D., & Liptak, G. (2009). Obesity across the lifespan among persons with spina bifida. *Disability Rehabilitation*, 31 (9), 914 – 920. doi: 10.1080/09638280802356476
- Dowda, M., Pate, R., Sallis, J., Freedson, P., & Taylor, W. (2007). Agreement between student reported and proxy-reported physical activity questionnaires. *Pediatric Exercise Science*, 19 (3), 310 – 318.
- Elliott, S., Baxter, K., Davies, P., & Truby, H. (2014). Accuracy of self-reported physical activity levels in obese adolescents. *Journal of Nutritional Metabolism*, 2014. doi: 10.1155/2014/808659
- Elliott, S., Davidson, Z., Davies, P., & Truby, H. (2015). Accuracy of parent-reported energy intake and physical activity levels in boys with duchenne muscular dystrophy. *Nutrition in Clinical Practice*, 30 (2), 297 – 304. doi: 10.1177/0884533614546696
- Haskell, W. (2012). Physical activity by self-report: A brief history and future issues. *Journal of Physical Activity and Health*, 9 (Suppl 1), S5 – 10. doi: 10.1123/jpah.9.s1.s5
- Hong, L. (2012). Obesity in children with down syndrome: Evaluation of measurements for nutrition assessment anthropometry, body composition, and energy expenditure. *Topics in Clinical Nutrition*, 27 (1), 48 – 53. doi: 10.1097/TIN.0b013e3182461dec
- McCann, D., Bull, R., & Winzenberg, T. (2012). The daily patterns of time use for parents of children with complex needs: A systematic review. *Journal of Child Health Care*, 16 (1), 26 – 52. doi: 10.1177/1367493511420186
- Ogden, C., Carroll, M., Kit, B., & Flegal, K. (2014). Prevalence of childhood and adult obesity in the United States, 2011–2012. *Journal of American Medical Association*, 322, 806 – 814. doi: 10.1001/jama.2014.732
- Physical Activities Guidelines Advisory Committee. (2008). *Physical Activity Guidelines Advisory Committee Report*. Washington (DC) : US Department of Health and Human Services. Retrieved from <https://health.gov/paguidelines/2008/report/>.
- Polfuss, M., Sawin, K., Papanek, P., Bandini, L., Forseth, B., Moosereiner, A., & Schoeller, D. (2017). Total energy expenditure and body composition of children with developmental disabilities. *Disability and Health Journal*, 11 (3), 442 – 446. doi: 10.1016/j.dhjo.2017.12.009
- Rebholz, C., Chinapaw, M., van Stralen, M., Bre, E., Bringolf, B., De Bourdeaudhuij, I., & Velde, S. (2014). Agreement between parent and child report on parental practices regarding dietary, physical activity and sedentary behaviours: The ENERGY cross-sectional survey. *BMC Public Health*, 14, 918. doi: 10.1186/1471-2458-14-918
- Teder, M., Mörelius, E., Bolme, P., Nordwall, M., Ekberg, J., & Timpka, T. (2013). Family based behavioural intervention program for obese children: An observational study of child and parent lifestyle interpretations. *PLoS one*, 8 (8). doi: 10.1136/bmjopen-2011-000268
- Thorn, J. E., DeLellis, N., Chandler, J., & Boyd, K. (2013). Parent and child self-reports of dietary behaviors, physical activity, and screen time. *Journal of Pediatrics*, 162 (3), 557 – 561. doi: 10.1016/j.jpeds.2012.08.031
- Tucker, C., Bevans, K., Teneralli, R., Smith, A., Bowles, H., & Forrest, C. (2014). Self-reported pediatric measures of physical activity, sedentary behavior, and strength impact for PROMIS: Conceptual framework. *Pediatric Physical Therapy*, 26 (4), 376 – 384. doi: 10.1097/PEP.0000000000000073
- Van Riper, M., & Cohen, W. (2001). Caring for children with Down syndrome and their families. *Journal of Pediatric Health Care*, 15 (3), 123 – 131. doi: 10.1067/mpH.2001.110627
- Vandelanotte, C., & Bourdeaudhuij, I. (2003). Acceptability and feasibility of a computer tailored physical activity intervention using stages of change: Project FAITH. *Health Education Research*, 18 (3), 304 – 317. doi: 10.1093/her/cyf027
- Warner, E., Wolin, K., Duncan, D., Heil, D., Askew, S., & Bennett, G. (2012). Differential accuracy of physical activity self-report by body mass index. *American Journal of Health Behavior*, 36 (2), 168 – 178. doi: 10.5993/AJHB.36.2.3

- Weinreich, N. K. (1999). Pretesting. In L. C. Shaw (Ed.), *Hands-on social marketing: A step-by-step guide* (pp. 123 – 156). Thousand Oaks, CA : Sage.
- Welk, G. (2002). *Physical activity assessments for health-related research*. Champaign, IL : Human Kinetics Publishers, Inc.