Journal on Developmental Disabilities
Le journal sur les handicaps du développement
JoDD
Volume 23, Number 2, 2018

# Exploratory, Pilot Study: Treatments Accessed by Caregivers of Children with Down Syndrome – An Internet Survey

Authors

Nicole Neil,[1]
Theresa Fiani,[2]
Arlene Mannion,[3]
Meagan Lynch[3]

[1] Faculty of Education, Western University, London ON

[2] Department of Psychology, The Graduate Center, City University of New York, New York NY

[3] School of Psychology, National University of Ireland, Galway IE

Correspondence

nneil@uwo.ca

Keywords

Down syndrome,
treatment,
survey,
caregiver



## Abstract

*Down syndrome is associated with a range of developmental strengths and challenges. The treatment use of individuals with Down syndrome along with associated factors have not yet been determined. In a pilot study to address this issue, we elected to conduct an online survey rather than a classical representative population survey to generate relevant information quickly. An online survey was completed by 162 primary caregivers of children and youth with Down syndrome. Caregivers reported the types of treatments children were currently receiving and had received in the past, along with the overall satisfaction with treatments. Associations with other child variables (e.g., age, gender, and race) and family characteristics were also examined. Findings indicate that children were currently receiving a mean of 6.1 (SD = 3.5) different types of therapy treatments; the most common treatments was speech–language therapy currently received by 73%. Only 2.4% of children were currently receiving applied behaviour analytic treatment, an empirically supported therapy. Caregivers reported using a number of treatments without empirical support including facilitated communication, holding therapy, and auditory/sensory integration. Caregivers tended to agree that each treatment was efficacious and contributed to their child's growth. Treatments that were associated with strong agreement included medication (69.8%), care from family and friends (62.8%), assistive technology (58.3%), and floortime (55.6%). Future research should focus on understanding the process of treatment selection by caregivers of children with Down syndrome and develop accessible guidelines on empirically supported therapies.*

Down syndrome (DS), one of the most common chromosomal abnormalities, is associated with physical co-morbidities such as heart defects and reduced immunological function (Kent, Evans, Paul, & Sharp, 1999) and a characteristic behavioural phenotype including weaknesses in communication (e.g., expressive language), cognition (e.g., verbal short-term memory), and motor (e.g., low muscle tone) domains (Fidler, 2005), which warrant intervention.

The varied physical, intellectual and behavioural challenges associated with DS necessitate a variety of individualized treatments. Caregivers of children with disabilities regularly report a dearth of information, making treatment selection difficult (Hummelinck & Pollock, 2006; Nordfeldt, Ängarne-Lindberg, Nordwall, & Krevers, 2013), exacerbated by negative attitudes and low expectations among treatment providers (Prussing, Sobo, Walker, & Kurtin, 2005). Thus, they

independently seek information (often from a vast array on the internet) to advocate for their child's best interests (Alsem et al., 2017; Prussing et al., 2005). This task can quickly become overwhelming and may lead to pursuit of treatments not known to have any beneficial effects or that might even be iatrogenic.

Extant treatment literature empirically supports the efficacy of some treatments (Lemons, Powell, King, & Davidson 2015; Millar, Light, & Schlosser, 2016; Neil & Jones, 2016) including applied behaviour analysis (Neil & Jones, 2016) and reading and phonological awareness treatments (Burgoyne et al., 2012), which target a range of weaknesses including communication (Bauer & Jones, 2015; Feeley, Jones, Blackburn, & Bauer, 2011; Jones, Feeley, & Blackburn, 2010), reading (Burgoyne et al., 2012; Naess, Melby-Lervag, Hulme, & Lyster, 2012), phonological awareness (Burgoyne et al., 2012), and mathematics (Lemons et al., 2015). Unfortunately, treatments established as ineffective for DS continue to be provided. Some of these treatments are considered controversial (Nickel, 1996) and are not recommended because of ineffectiveness or potential harm for individuals with developmental disabilities (Mercer, 2001; Mostert, 2001). These include facilitated communication, where communication is mediated via pointing and typing by a "facilitator," and holding therapy, consisting of forced holding by a therapist for a fixed period of time or until resistance stops. Others, such as sensory/auditory integration training lack support for individuals with DS (Baranek, 2002; Dawson & Watling, 2000; Lang et al., 2012). In this treatment, individuals are repeatedly and systematically exposed to sensory stimulation.

To provide guidance for treatment professionals, facilitate evidence-based practice, and encourage research into under-examined treatments, we sought to better understand: (1) the number and types of treatments utilized by caregivers of children with DS; (2) how child characteristics influence the number of treatments used; and (3) how caregivers rate treatment efficacy. An Internet survey was used to answer these questions. In certain situations, this method of online data collection can provide valuable information for research (Gosling, Vazire, Srivastava, & John, 2004; Preckel & Thiemann, 2003) and is a frequently used tool in behavioural research (Granello & Wheaton, 2004).

# Materials and Methods

## Participants

Participants included 162 primary caregivers of children with DS in their household. Sociodemographic information was collected for primary and secondary caregivers and for children with DS. Survey information was provided by the primary caregivers. Of children whose gender was reported ($n$ = 138), the average age was 7.35 years ($SD$ = 4.95, range = 0–17); 53.6% ($n$ = 74) were boys and 46.4% ($n$ = 64) were girls. Families most commonly reported white racial/ethnic backgrounds (92.8%, $n$ = 128), whereas 7.2% were families of colour (e.g., Black, Asian/Pacific Islander). For detailed socio-demographic breakdown including the primary caregiver, secondary caregiver, and child characteristics, refer to Table 1 on page 42. Participants presented with a wide range of co-morbid diagnoses including attention-deficit/hyperactivity disorder, autism spectrum disorder (ASD), and cystic fibrosis; refer to Table 2 on page 44 for more details.

## Materials

The first and third authors developed the questionnaire (available on request) based on existing literature investigating caregiver treatment use among individuals with other developmental disabilities (Green et al., 2006; Goin-Kochel, Mackintosh, & Myers, 2009; Hume, Bellini, & Pratt, 2005; Martin et al., 2013). Twenty-five questions assessed demographic characteristics of primary and secondary caregivers and the child with DS (e.g., country of residence, age, gender, race/ethnicity, education, marital status). Caregivers selected from a list of 35 treatments those which their child/family was receiving/had received, and rated each treatment's effectiveness by indicating their agreement with the following statement: "This treatment was effective and contributed to my child's growth" on a five-point Likert scale (1 = strongly disagree). The generic "growth" term was used so that families could apply the statement to multiple types of treatment. However, the ratings do not tell us what specific behaviors primary caregivers saw as changed due to a given treatment/therapy, though the caregivers might have had a specif-

ic behaviour or behaviours in mind when they responded. For example, caregivers were most likely indicating growth in language and communication as a result of speech therapy.

## Procedures

The web-based survey was distributed via chapters of the Global DS Foundations [http://www.globaldownsyndrome.org], and via colleagues, who then distributed it to caregivers of children with DS. The survey was live from June 2016 to January 2017. Participants accessed the questionnaire after providing informed consent, and all submitted responses were stored on a secure, university-controlled server. Participation was confidential, as no identifying information as collected. Participants did not receive compensation. Statistical analyses were interpreted at the 95% confidence level. The study protocol was reviewed and approved by the Institutional Review Board at Michigan State University.

# Results

## Treatments

Note: Percentages were based upon 162 submitted surveys. In families with more than one child with Down syndrome, the average number of particular treatments per child was used in the analysis. In some cases a primary caregiver did not indicate (a) current, (b) past, or (c) never for a particular treatment. Such omissions were classified as missing data. As a result of missing data, the sample sizes varied across treatment. Zeros represent no primary caregivers reporting use of that treatment.

**Treatment Use.** At least one primary caregiver endorsed each of the 35 treatments listed in the survey (see Table 3 on page 45 for rank order of treatments used). The most common treatment, speech therapy, was presently used by 73% of caregivers and previously used by 19%. The next most commonly currently used treatments were care from family or friends, occupational therapy, and physical therapy. On average, caregivers reported currently using six treatments ($M$ = 6.1, $SD$ = 3.5, range = 0–20), higher than mean past treatments ($M$ = 5.1, $SD$ = 4.3, range 0–23).

A three-way analysis of variance tested the effects of age, gender, and race on number of current treatments. As shown in Table 4 on page 46, main effects of age and race were not statistically significant, however, girls ($M$ = .85, $SD$ = .06) received significantly more treatments than boys ($M$ = .69, $SD$ = .05), $F$ (1, 133) = 5.25, $p$ = .02, $\eta^2$ = .04. Figure 1 depicts current treatments by gender. As depicted in Figure 2 on the following page, there was a significant interaction between age group and race, $F$ (2, 133) = 5.23, $p$ = .007, $\eta^2$ = .08. For 0–6 year olds, white caregivers ($M$ = .80, $SD$ = .03) reported significantly more current treatments than caregivers of colour ($M$ = .62, $SD$ = .08), $p$ = .046. In 7–12 year olds, caregivers of colour ($M$ = .91, $SD$ = .10) reported significantly more current treatments than white caregivers ($M$ = .69, $SD$ = .05), $p$ = .05. There were no significant differences in current treatments between white caregivers ($M$ = .66, $SD$ = .05) and caregivers of colour ($M$ = .93, $SD$ = .15) for the age group of 13–18 years old. In white caregivers, 0–6 year olds received significantly more interventions than 13–18 year olds ($p$ = .030). In caregivers of colour, 0–6 year olds received significantly more interventions than 7–12 years old ($p$ = .030).

**Caregiving Ratings of Treatment Efficacy.** Figure 3 on page 41 shows caregiver ratings of the efficacy of treatments and contribution

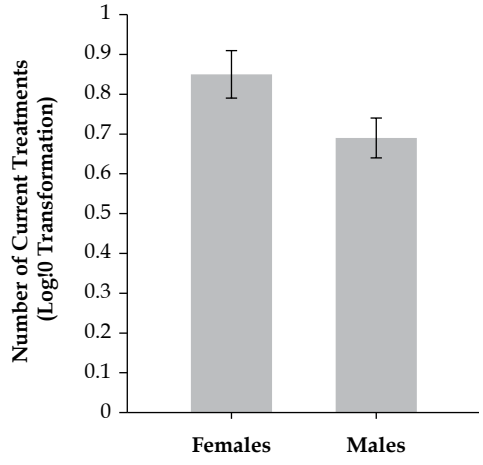


*Figure 1. Number of caregiver reported treatments currently being used by gender. Error bars represent the standard error of the mean.*

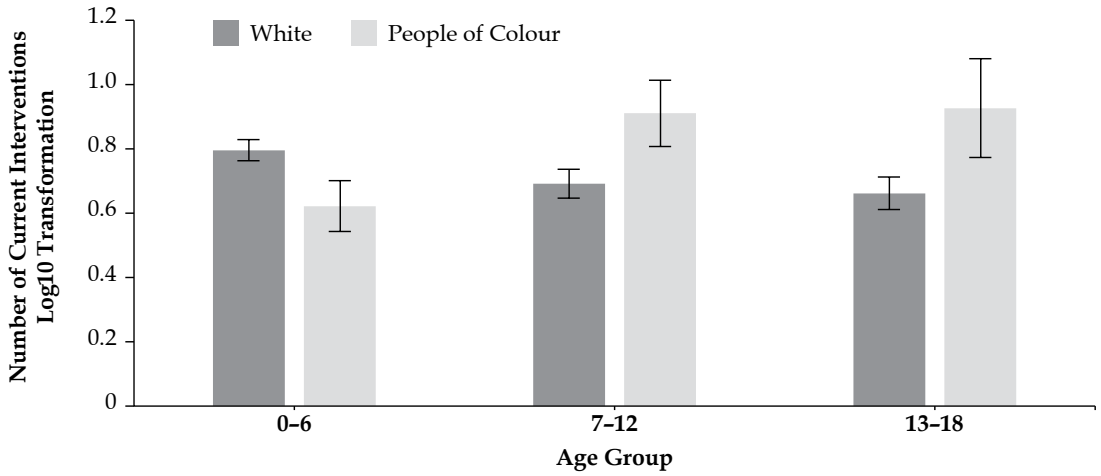


*Figure 2. Number of primary caregiver reported treatments currently being used by age group and race. Error bars represent the standard error of the mean.*

to their child's growth. Most family members agreed that each treatment was efficacious and contributed to growth. Caregivers strongly supported medication (69.8%), care from family and friends (62.8%), assistive technology (58.3%), and floortime (55.6%) as effective contributors to their child's development. Caregivers also strongly supported holding therapy (100%) though this was used only by three families. The rates of strong disagreement for effectiveness of specific therapies were much lower than for the rates of strong agreement. The highest rate of caregivers (6.3%) strongly disagreed that family counselling significantly impacted their child's growth. Adaptive physical education and social skills training also had higher dissatisfaction rates (5.3% and 5.0% strongly disagreed, respectively).

## Discussion

This study sought to better understand: (1) the number and types of treatments utilized by caregivers of children with DS; (2) how child characteristics influence the number of treatments used; and (3) how caregivers rate treatment efficacy. Some treatments accessed by families were empirically supported, while others were not. The most commonly used treatment was speech therapy, consistent with communication problems as characteristic among individuals with DS (Fidler, 2005). Fortunately, speech therapy is empirically validated (Kumin, 1999; Rondal & Buckley, 2003) for DS. Least common treatments included applied behaviour analysis, despite extensive empirical support for the use of applied behaviour analysis for individuals with DS (for systematic review, see Neil & Jones, 2016). Several reported current and past treatments are not evidence-based for use with children with DS. Almost 10% of the participants reported current use of facilitated communication, despite extensive data against its effectiveness (Bligh & Kupperman, 1993; Cabay, 1994; Eberlin, McConnachie, Ibel, & Volpe, 1993; Tostanoski, Lang, Raulston, Carnett, & Davis, 2014). Additional treatments which persisted despite lack of evidence-base included craniosacral/myofascial (Ernst, 2012; Hartman, 2006), auditory and sensory integration (Baranek, 2002; Dawson & Watling, 2000) and supplement use (Salman, 2002).

It is possible that a lack of information, or poorly disseminated information regarding evidence-based treatments for children with DS contributes to the continued use of non-evidence based treatments by treatment providers and caregivers. Additionally, high motivation to improve quality of life for their children may motivate caregivers to try treatments based upon advertisement or perceived availability, regardless of empirical support (Prussing et al., 2005).

Our results indicate caregivers of children with DS were using an average of five different treatments simultaneously. While multiple

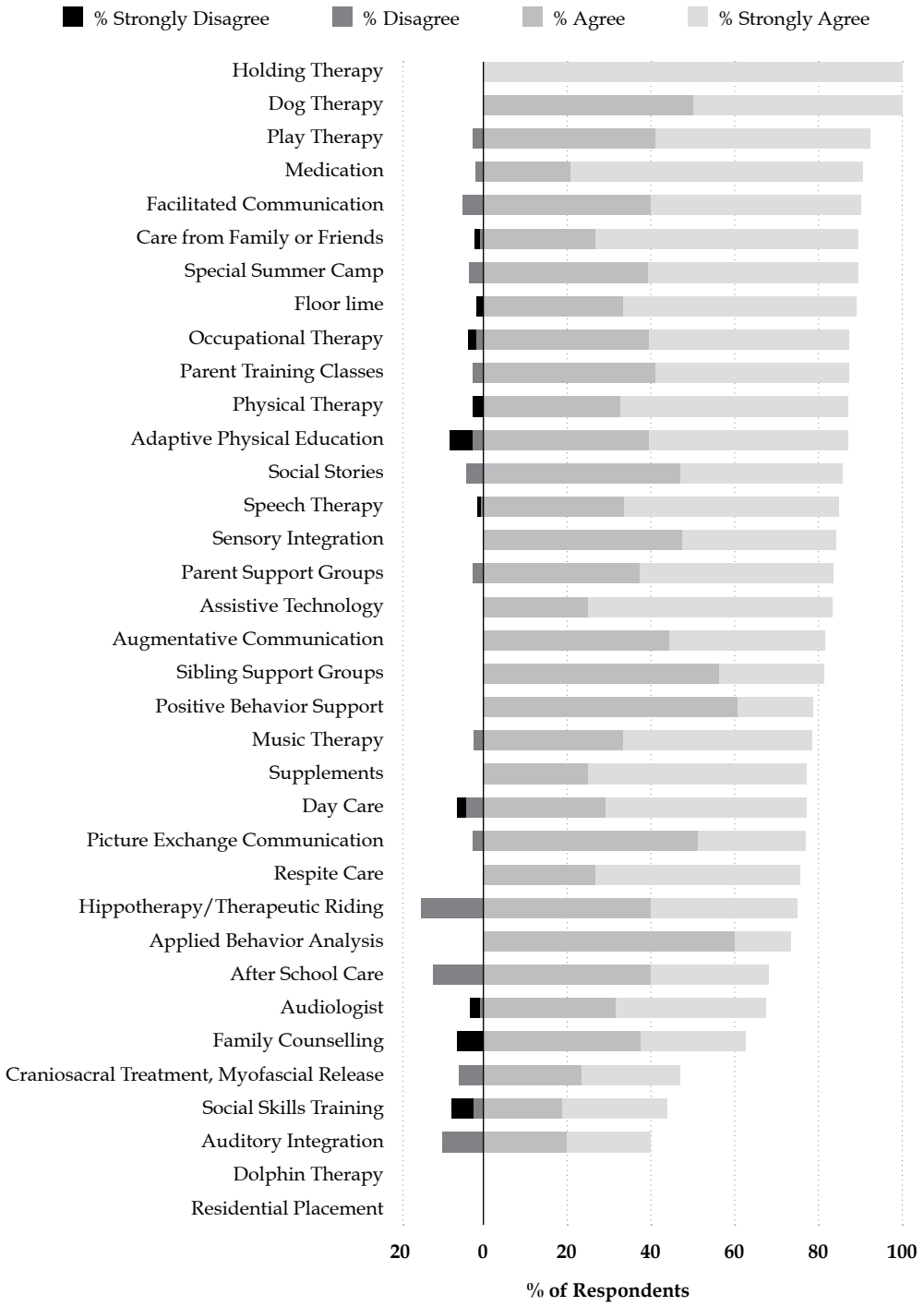


*Figure 3. Responses of participants who use/have used treatment to the statement, "This treatment was effective and contributed to my child's growth." Note: In some cases a primary caregiver did not indicate (a) current, (b) past, or (c) never for a particular treatment. Such omissions were classified as missing data. As a result of missing data, the sample sizes varied across treatment. Data for neither agree/nor disagree is not represented in the figure. The lack of information for dolphin therapy and residential therapy reflects all caregivers indicating neither agree/nor disagree.*

*Table 1. Demographic Characteristics of the Primary and Secondary Caregiver and Children with Down Syndrome*

| | *Number* | *Percent* | *Mean* | *Standard Deviation* |
|---|---|---|---|---|
| *Primary Caregiver* | | | | |
| Country of Residence | | | | |
| United States | 81 | 50.0 | | |
| Canada | 16 | 9.9 | | |
| Ireland | 23 | 14.2 | | |
| United Kingdom | 6 | 3.7 | | |
| Australia | 5 | 3.1 | | |
| Andorra | 1 | 0.6 | | |
| China | 1 | 0.6 | | |
| France | 1 | 0.6 | | |
| Greece | 1 | 0.6 | | |
| Poland | 1 | 0.6 | | |
| Romania | 1 | 0.6 | | |
| South Africa | 1 | 0.6 | | |
| Gender | | | | |
| Female | 121 | 87.7 | | |
| Male | 17 | 12.3 | | |
| Age (years) | | | 41.5 | 9.4 |
| Race/Ethnicity | | | | |
| White | 128 | 92.8 | | |
| Black or African American | 3 | 2.2 | | |
| Asian | 3 | 2.2 | | |
| American Indian or Alaska Native | 1 | 0.7 | | |
| Other | 3 | 2.1 | | |
| Relationship Status | | | | |
| Married | 112 | 81.2 | | |
| Divorced | 11 | 8.9 | | |
| Never married | 9 | 5.6 | | |
| Separated | 4 | 2.5 | | |
| Widowed | 2 | 1.4 | | |
| Educational Level | | | | |
| Less than high school | 2 | 1.4 | | |
| High school graduate | 9 | 6.5 | | |
| Educational level beyond high school | 127 | 78.4 | | |
| Children in household | | | | |
| One | 46 | 33.3 | | |
| Two | 47 | 34.1 | | |
| Three | 33 | 23.9 | | |
| Four | 6 | 4.3 | | |
| Five | 6 | 4.3 | | |

*Table 1. Demographic Characteristics of the Primary and Secondary Caregiver and Children with Down Syndrome* (continued)

| | | | | |
|---|---|---|---|---|
| *Secondary Caregiver* | | | | |
| Gender | | | | |
| Female | 97 | 86.6 | | |
| Male | 15 | 13.4 | | |
| Age (years) | | | 43.7 | 8.6 |
| Race/Ethnicity | | | | |
| White | 102 | 91.1 | | |
| Black or African American | 4 | 3.6 | | |
| Asian | 2 | 1.8 | | |
| Other | 4 | 3.6 | | |
| Relationship Status | | | | |
| Married | 105 | 93.8 | | |
| Divorced | 4 | 3.6 | | |
| Never married | 2 | 1.8 | | |
| Separated | 1 | 0.9 | | |
| Educational Level | | | | |
| Less than high school | 2 | 1.8 | | |
| High school graduate | 13 | 11.6 | | |
| Educational level beyond high school | 97 | 86.6 | | |
| *Children with DS* | | | | |
| Gender | | | | |
| Males | 74 | 53.6 | | |
| Females | 64 | 46.4 | | |
| Age (years) | | | 7.4 | 5.0 |
| Race/Ethnicity | | | | |
| White | 117 | 84.8 | | |
| Black or African American | 5 | 3.6 | | |
| Asian | 4 | 2.9 | | |
| American Indian or Alaska Native | 2 | 1.4 | | |
| Native Hawaiian or Pacific Islander | 1 | 0.8 | | |
| Other | 9 | 6.5 | | |
| Has DS Plus One or More Additional Diagnoses | 31 | 22.5 | | |
| Number of Children with DS in Household | | | | |
| One child with DS | 135 | 97.8 | | |
| Two or more children with DS | 3 | 2.2 | | |

*Note: Primary caregivers completed the survey. Secondary caregiver information was reported by the primary caregiver.*

*Table 2. Diagnoses Reported by Caregivers of Children with DS.*

| *Diagnosis* | *Number* | *Percentage* |
|---|---|---|
| Only Down syndrome | 107 | 77.5 |
| Co-occurring diagnosis | 31 | 22.5 |
| Autism spectrum disorder | 6 | 19.4 |
| Apraxia | 3 | 9.7 |
| Attention-deficit/ hyperactivity disorder | 3 | 9.7 |
| Sensory processing disorder | 3 | 9.7 |
| Sleep apnea | 3 | 9.7 |
| Anxiety disorders | 2 | 6.5 |
| Cerebral palsy | 2 | 6.5 |
| Epilepsy | 2 | 6.5 |
| Cystic fibrosis | 1 | 3.2 |
| Dyslexia | 1 | 3.2 |
| Ehler-Danlos syndrome | 1 | 3.2 |
| Global delayed learning | 1 | 3.2 |
| Graves' disease | 1 | 3.2 |
| Heart defect | 1 | 3.2 |
| Hashimoto's disease | 1 | 3.2 |
| Hydrocephalus | 1 | 3.2 |
| Hypothyroidism | 1 | 3.2 |
| Leukemia | 1 | 3.2 |
| Nystagmus | 1 | 3.2 |

*Note: In some cases a caregiver reported multiple co-occurring diagnoses for a child. As a result the sum of percentages is greater than 100%.*

treatments may have positive effects if those treatments are evidence-based, as one treatment may bolster the effects of another, in some cases multiple treatments may be contraindicated. Additionally, the use of multiple simultaneous therapies poses a methodological challenge, as the effects of evidence-based treatments may be masked or misattributed to non-evidence-based treatments. For example, caregivers often seek evidence-based treatments targeting speech, language, motor skills, communication and challenging behaviour (e.g., speech and language therapy; Kumin, 2012; Rondal & Buckley, 2003; physical therapy; and applied behaviour analysis; Bauer, Jones, & Feeley, 2014; Feeley & Jones, 2006; Neil & Jones, 2016), coupled with treatments that are not evidence-based (e.g., facilitated communication, sensory/auditory integration, and craniosacral/myofascial; Ernst, 2012). Confounding effects across treatments may account for positive caregiver ratings across treatments regardless of empirical support, as caregivers may misattribute treatment gains to non-evidence-based treatments.

The average number of currently used treatments varied as a function of the child's age, race, and gender. Female children with DS were currently receiving more treatments than male children with DS. While research on gender differences in DS is scarce, one study suggests that girls with DS score higher on language measures (Berglund, Eriksson, & Johansson, 2001). Thus, it is paradoxical that girls receive more interventions than boys, despite evidence (albeit preliminary) that boys display greater impairments. Future research and interventions should seek to expand interventions to target boys with DS who may be of greater need, as well as to better understand gender differences in DS presentations and treatments.

Additionally, white caregivers reported significantly more treatments than caregivers of colour when their children were 0–6 years old, a pattern which reversed among children 7–12 years old, before equalizing at ages 13–18. Although few people of colour participated in the study, cultural differences may have impacted our results. For example, people of colour tend to be more collectivists (i.e., they keep concerns within families), which may explain why they did not access early intervention like white caregivers who generally tend to seek outside expertise in addition to family support. Furthermore, it may be that the caregivers are not informed about the ways to access early intervention. However, it is possible that these results are an artifact of our non-representative sample, which was largely comprised of white children (84.8%). This limita-

*Table 3. Rank Order of Treatments in Terms of Percentage of Primary Caregivers Reporting Use*

| *No.* | *Treatment Name* | *% Currently Using* | *% Used in the Past* |
|---|---|---|---|
| 1 | Speech Therapy | 73.0 | 19.7 |
| 2 | Care From Family or Friends | 57.7 | 20.8 |
| 3 | Occupational Therapy | 51.1 | 35.8 |
| 4 | Physical Therapy | 50.4 | 42.1 |
| 5 | Audiologist | 39.1 | 34.6 |
| 6 | Parent Support Groups | 38.2 | 25.2 |
| 7 | Medication | 35.1 | 9.2 |
| 8 | Supplements | 33.8 | 6.9 |
| 9 | Adaptive Physical Education | 22.5 | 9.3 |
| 10 | Assistive Technology | 19.4 | 11.6 |
| 11 | Floortime | 19.1 | 32.8 |
| 12 | Respite Care | 18.9 | 15.9 |
| 13 | Social Stories | 18.1 | 23.6 |
| 14 | Social Skills Training | 18.0 | 11.7 |
| 15 | Day Care | 15.9 | 24.2 |
| 16 | After School Care | 14.3 | 8.3 |
| 17 | Picture Exchange Communication | 13.8 | 19.2 |
| 18 | Music Therapy | 13.7 | 19.8 |
| 19 | Positive Behaviour Support | 13.2 | 10.9 |
| 20 | Augmentative Communication | 12.3 | 11.5 |
| 21 | Play Therapy | 12.2 | 19.1 |
| 22 | Facilitated Communication | 9.3 | 9.3 |
| 23 | Special Summer Camp | 9.2 | 14.5 |
| 24 | Parent Training Classes | 6.9 | 24.4 |
| 25 | Dog Therapy | 6.9 | 2.3 |
| 26 | Craniosacral Treatment, Myofascial Release | 6.1 | 8.4 |
| 27 | Hippotherapy/Therapeutic Riding | 3.8 | 13.0 |
| 28 | Sensory Integration | 3.8 | 12.9 |
| 29 | Sibling Support Groups | 3.1 | 10.0 |
| 30 | Applied Behaviour Analysis | 3.1 | 11.0 |
| 31 | Family Counselling | 2.3 | 13.1 |
| 32 | Auditory Integration | 1.5 | 6.9 |
| 33 | Holding Therapy | 0.8 | 1.5 |
| 34 | Dolphin Therapy | 0 | 1.5 |
| 35 | Residential Placement | 0 | 0.8 |

*Table 4. Analysis of Variance for Total Number of Current Treatments (n = 133)*

| *Source* | *df* | *F* | *p* |
|---|---|---|---|
| Age Category | 2 | 1.03 | .363 |
| Race | 1 | 2.08 | .152 |
| Gender | 1 | 5.25* | .024* |
| Age Category×Race | 2 | 5.23* | .007* |
| Age Category×Gender | 2 | 1.45 | .238 |
| Race×Gender | 1 | .623 | .432 |
| Age Category×Race×Gender | 2 | .639 | .530 |
| Error | 121 | (.063) | |
| Total | 133 | | |

*Note: Analyses based upon log10-transformed data; Value in parentheses represents the mean square error; "*" p is significant; "×" refers to test of interaction between sources.*

tion may impact the generalizability of our findings regarding race. Thus, the following results while preliminary warrant further investigation to help clinicians and researchers more effectively disseminate information and services to families from diverse racial/ethnic backgrounds.

Albeit preliminary and part of a scarce pool of research, our results regarding rates of treatment participation among children with DS are consistent with other developmental disabilities. For example, children with autism spectrum disorder (ASD) generally have higher mean number of current and past treatments (7 and 8 respectively) than children with DS (Green et al., 2004). It may be that children with ASD are referred for treatment more frequently due to challenging behaviours and noteworthy social impairments, whereas children with DS may appear to only have significant language impairments (Sigman et al., 1999). For children with ASD speech therapy, visual schedules, sensory integration and applied behavior analysis were the four most commonly used treatments (Green et al., 2004). In another study, caregivers showed strong support for parent training, speech therapy, sensory integration and discrete trial teaching (Hume et al., 2005). Only speech therapy was common among the most frequently used treatments for children with DS.

This study has several limitations. Caregivers of children with DS may not be reliable or accurate evaluators of their child's actual developmental outcomes and future research is needed to determine how perceptions of outcomes relate to valid measures of outcomes and treatment selection. The sample selection method also presents limitations. Participants in this study may reflect a non-representative subgroup of families with children with Down syndrome, as all participants had access to the internet and were recruited from DS advocacy agency websites and mailing lists. This is reflected in the lack of variability in gender and educational level of the participants. Participants may also be more informed regarding treatment treatments as they received regular informational mailings and access advocacy sites regularly. Response bias is another potential limitation in this study, as we were unable to assess caregiver understanding of described treatments listed.

In summary caregivers of children with Down syndrome access a wide variety of treatments with and without empirical support for their use. Caregivers of children with Down syndrome need access to educational materials surrounding specific treatments, presented in a manner that is easily understood. The number of treatments currently being used by caregivers varied with characteristics of the child with Down syndrome indicating access to information and services varies with child characteristics. There is a need for additional research to understand how caregivers select treatment for their children with Down syndrome. Identifying the variables that influence decision-making will help inform promotional practices aimed at increasing the use of empirically supported treatments among children with Down syndrome.

## Key Messages From This Article

**People with disabilities.** If you are seeking help, you deserve to have a treatment that works and is a good fit for you as a person.

**Professionals.** Treatment for children with Down syndrome should be evidence-based, Information about the effectiveness of treatments should be provided to families to assist in treatment decision making.

**Policymakers.** Families of children with Down syndrome are accessing a wide variety of effective and noneffective treatments. Increased policies are needed that specify the use of evidence-based treatments for children with Down syndrome.

## References


Alsem, M. W., Ausems, F., Verhoef, M., Jongmans, M. J., Meily-Visser, J. M. A., & Ketelaar, M. (2017). Information seeking by parents of children with physical disabilities: An exploratory qualitative study. *Research in Developmental Disabilities*, *60*, 125–134. doi:10.1016/j.ridd.2016.11.015

Baranek, G. T. (2002). Efficacy of sensory and motor interventions for children with autism. *Journal of Autism and Developmental Disorders, 32*, 397–422. doi:10.1023/A:1020541906063

Bauer, S. M., & Jones, E. A. (2015). Requesting and verbal imitation intervention for infants with Down syndrome: Generalization, intelligibility, and problem solving. *Journal of Developmental and Physical Disabilities*, *27*, 37–66. doi:10.1007/s10882-014-9400-6

Bauer, S. M., Jones, E. A., & Feeley, K. M. (2014). Teaching responses to questions to young children with Down syndrome. *Behavioural Interventions*, *29*, 36–49. doi:10.1002/bin.1368

Berglund, E., Eriksson, M., & Johansson, I. (2001). Parental reports of spoken language skills in children with Down syndrome. *Journal of Speech, Language, and Hearing Research*, *44*, 179–191. doi:10.1044/1092-4388(2001/016)

Bligh, S., & Kupperman, P. (1993). Brief report: Facilitated communication evaluation procedure accepted in a court case. *Journal of Autism and Developmental Disorders*, *23*, 553–557. doi:10.1007/BF01046056

Burgoyne, K., Duff, F. J., Clarke, P. J., Buckley, S., Snowling, M. J., & Hulme, C. (2012). Efficacy of a reading and language intervention for children with Down syndrome: A randomized controlled trial. *Journal of Child Psychology and Psychiatry and Allied Disciplines*, *53*, 1044–1053. doi:10.1111/j.1469-7610.2012.02557.x

Cabay, M. (1994). Brief report: A controlled evaluation of facilitated communication using open-ended and fill-in questions. *Journal of autism and developmental disorders*, *24*, 517–527. doi:10.1007/BF02172132

Dawson, G., & Watling, R. (2000). Interventions to facilitate auditory, visual, and motor integration in autism: A review of the evidence. *Journal of autism and developmental disorders, 30*, 415–421. doi:10.1023/A:1005547422749

Eberlin, M., McConnachie, G., Ibel, S., & Volpe, L. (1993). Facilitated communication: A failure to replicate the phenomenon. *Journal of autism and developmental disorders*, *23*, 507–530. doi:10.1007/BF01046053

Ernst, E. (2012). Craniosacral therapy: A systematic review of the clinical evidence. *Focus on Alternative and Complementary Therapies*, *17*, 197–201. doi:10.1111/j.2042-7166.2012.01174.x

Feeley, K. M., Jones, E. A., Blackburn, C., & Bauer, S. (2011). Advancing imitation and requesting skills in toddlers with Down syndrome. *Research in Developmental Disabilities*, *32*, 2415–2430. doi:10.1016/j.ridd.2011.07.018

Feeley, K., & Jones, E. (2006). Addressing challenging behaviour in children with Down syndrome: The use of applied behaviour analysis for assessment and intervention. *Down Syndrome Research and Practice*, *11*, 64–77. doi:10.3104/perspectives.316

Fidler, D. J. (2005). The emerging Down syndrome behavioural phenotype in early childhood. *Infants & Young Children*, *18*, 86–103. doi:10.1097/00001163-200504000-00003

Goin-Kochel, R. P., Mackintosh, V. H., & Myers, B. J. (2009). Parental reports on the efficacy of treatments and therapies for their children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, *3*, 528–537. doi:10.1016/j.rasd.2008.11.001

Gosling, S. D., Vazire, S., Srivastava, S., & John, O. P. (2004). Should we trust web-based studies? A comparative analysis of six preconceptions about internet questionnaires. *American Psychologist*, *59*(2), 93–104. doi:10.1037/0003-066X.59.2.93

Granello, D. H., & Wheaton, J. E. (2004). Online data collection: Strategies for research. *Journal of Counseling & Development*, *82*, 387–393. doi:10.1002/j.1556-6678.2004.tb00325.x

Green, V. A., Pituch, K. A., Itchon, J., Choi, A., O'Reilly, M., & Sigafoos, J. (2006). Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities*, *27*, 70–84. doi:10.1016/j.ridd.2004.12.002

Hartman, S. E. (2006). Cranial osteopathy: Its fate seems clear. *Chiropractic & Osteopathy*, *14*(1), 10. https://doi.org/10.1186/1746-1340-14-10

Hume, K., Bellini, S., & Pratt, C. (2005). The usage and perceived outcomes of early intervention and early childhood programs for young children with autism spectrum disorder. *Topics in Early Childhood Education, 25*, 195–207. doi:10.1177/02711214050250040101

Hummelinck, A., & Pollock, K. (2006). Parents' information needs about the treatment of their chronically ill child: A qualitative study. *Patient education and counseling*, *62*, 228–234. doi:10.1016/j.pec.2005.07.006

Jones, E., Feeley, K., & Blackburn, C. (2010). A preliminary study of intervention addressing early developing requesting behaviours in young infants with Down syndrome. *Down Syndrome Research and Practice*, *12*(2), 98–102. doi:10.3104/reports.2059

Kent, L., Evans, J., Paul, M., & Sharp, M. (1999). Comorbidity of autistic spectrum disorders in children with Down syndrome. *Developmental Medicine & Child Neurology*, *41*, 153–158. doi:10.1093/eurpub/ckl103

Kumin, L. (1999). Comprehensive speech and language treatment for infants, toddlers, and children with Down syndrome. In T. J. Hassold & D. Patterson (Eds.), *Down syndrome: A promising future, together* (pp. 145–153). New York, NY: Wiley-Liss.

Lang, R., O'Reilly, M., Healy, O., Rispoli, M., Lydon, H., Streusand, W., … Giesbers, S. (2012). Sensory integration therapy for autism spectrum disorders: A systematic review. *Research in Autism Spectrum Disorders*, *6*, 1004–1018. doi:10.1016/j.rasd.2012.01.006

Lemons, C. J., Powell, S. R., King, S. A., & Davidson, K. A. (2015). Mathematics interventions for children and adolescents with Down syndrome: A research synthesis. *Journal of Intellectual Disability Research*, *59*, 767–783. doi:10.1111/jir.12188

Martin, G. E., Ausderau, K. K., Raspa, M., Bishop, E., Mallya, U., & Bailey, D. B. (2013). Therapy treatment use among individuals with fragile X syndrome: Findings from a US parent survey. *Journal of Intellectual Disability Research*, *57*, 837–849. doi:10.1111/j.1365-2788.2012.01608.x

Mercer, J. (2001). Attachment therapy using deliberate restraint: An object lesson on the identification of unvalidated treatments. *Journal of Child and Adolescent Psychiatric Nursing*, *14*, 105–114. doi:10.1111/j.1744-6171.2001.tb00302.x

Millar, D. C., Light, J. C., & Schlosser, R. W. (2006). The impact of augmentative and alternative communication intervention on the speech production of individuals with developmental disabilities: A research review. *Journal of Speech Language and Hearing Research*, *49*, 248–264. doi:10.1044/1092-4388(2006/021)

Mostert, M. P. (2001). Facilitated communication since 1995: A review of published studies. *Journal of Autism and Developmental Disorders*, *31*, 287–313. doi:10.1023/A:1010795219886

Naess, K. A., Melby-Lervag, M., Hulme, C., & Lyster, S. A. (2012). Reading skills in children with Down syndrome: A meta-analytic review. *Research in Developmental Disabilities*, *33*, 737–747. doi:10.1016/j.ridd.2011.09.019

Neil, N., & Jones, E. A. (2016). Communication intervention for individuals with Down syndrome: Systematic review and meta-analysis. *Developmental Neurorehabilitation*, *August 18*, 1–12. doi:10.1080/17518423.2016.1212947

Nickel, R. E. (1996). Controversial therapies for young children with developmental disabilities. *Infants & Young Children, 8*, 29–40.

Nordfeldt, S., Ängarne-Lindberg, T., Nordwall, M., & Krevers, B. (2013). Parents of adolescents with type 1 diabetes-their views on information and communication needs and internet use. A qualitative study. *PLoS One*, *8*(4), e62096.doi:10.1371/journal.pone.0062096

Preckel, F., & Thiemann, H. (2003). Online- versus paper-pencil version of a high potential intelligence test. *Swiss Journal of Psychology/Schweizerische Zeitschrift für Psychologie/Revue Suisse de Psychologie*, *62*, 131–138. doi:10.1024//1421-0185.62.2.131

Prussing, E., Sobo, E. J., Walker, E., & Kurtin, P. S. (2005). Between "desperation" and disability rights: A narrative analysis of complementary/alternative medicine use by parents for children with Down syndrome. *Social Science and Medicine*, *60*, 587–598. doi:10.1016/j.socscimed.2004.05.020

Rondal, J., & Buckley, S. (Eds.) (2003). *Speech and language intervention in Down syndrome*. London, UK: Whurr Publishers Ltd.

Salman, M. S. (2002). Systematic review of the effect of therapeutic dietary supplements and drugs on cognitive function in subjects with Down syndrome. *European Journal of Paediatric Neurology*, *6*, 213–219. doi:10.1053/ejpn.2002.0596

Sigman, M., Ruskin, E., Arbelle, S., Corona, R., Dissanayake, C., Espinosa, … Robinson, B.F. (1999). Continuity and change in the social competence of children with autism, Down syndrome, and developmental delays. *Monographs of the Society for Research in Child Development*, *64*(1), 1–139.

Tostanoski, A., Lang, R., Raulston, T., Carnett, A., & Davis, T. (2014). Voices from the past: Comparing the rapid prompting method and facilitated communication. *Developmental Neurorehabilitation*, *17*, 219–223. doi:10.3109/17518423.2012.749952