

LITERACY

Literacy environments for children with Down syndrome: What's happening at home?

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This descriptive study investigated the home literacy environment of New Zealand children with Down syndrome. Participants were 85 children with Down syndrome enrolled in predominantly mainstream school programmes in years 1-8, who were aged between 5;4 (y; m) and 14;11 (M = 8;11, SD = 2;6), comprising an estimated 15% of children with Down syndrome in New Zealand primary education^[1]. Survey data via questionnaire (modelled on Boudreau^[2]), was gathered from participant's parents and targeted three broad themes including parents' priorities regarding literacy for their child with Down syndrome, ways in which the HLE of children with Down syndrome supports literacy development and the ways children with Down syndrome participate in literacy interactions. Results were analysed for all participants and by age group which are presented when group differences were apparent. Results indicated the majority of parents are involved in regular literacy interactions with their child, although more with reading than with writing. Many children played an active role in joint reading activities, interacting with both pictures and text, although more with pictures than with text. Children were reported to use a wide range of writing materials. Parents also reported other ways in which they facilitated literacy development including active teaching, language games and library visits. Clinical implications for parents and professionals working with children with Down syndrome are discussed with reference to relationships between HLE variables and positive literacy outcomes and provide support for the development of targeted interventions specifically aimed at facilitating literacy with this population.

Introduction

Adopting a sociocultural approach to the acquisition of literacy has resulted in a shift in thinking from a 'reading readiness' model based on maturational level or the acquisition of a prerequisite set of skills^[3,4], to an 'emergent literacy' model^[5] which sees literacy as emerging from meaningful and functional interactions with print. This approach emphasises the role of daily literacy based experiences and interaction with adults as well as the child's active role in becoming literate. Thus, while children may not receive formal reading instruction until they start school, the process by which they learn to read can build on a range of earlier literacy experiences^[6].

There is a considerable body of evidence that suggests that the home literacy environment (HLE) is key to a child's emergent literacy^[7-9], and that the richness of that environment is deter-

mined by factors such as frequency of exposure to, and engagement with, literacy items including joint and independent reading; the importance placed on literacy in the home; socioeconomic status; and maternal education level^[10]. Emergent literacy skills, the precursors to conventional reading and writing skills, are generally accepted to include alphabet knowledge, concepts of print, phonological awareness, and vocabulary^[6]. Frijters, Barron and Brunello^[11] found strong relationships between children's home literacy and literacy interest measures and their letter knowledge, phonological awareness and vocabulary.

Joint book reading appears to be a key feature of the HLE, positively affecting the development of emergent literacy skills and accounting for approximately 8% of the variance in reading achievement^[12-14]. Additionally, shared story reading which targets the development of specific skills is successful in increasing children's

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doi:10.3104/reports.2111

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print awareness^[15,16], facilitating emergent phoneme awareness and letter knowledge^[17,18] and enhancing oral language skills^[14]. These findings are consistent with those of Sénéchal and colleagues^[8,19,20] who investigated the contributions of explicit teaching of reading and print (a formal literacy activity), and joint story reading (an informal literacy activity), to oral and written language development in young children. In a series of studies Sénéchal and colleagues^[8,19,20] found children's exposure to story reading was predictive of their oral language development but not their written language skills. By contrast, parent's reported teaching behaviours were predictive of children's written language skills but not their oral language development. As no correlation was found between the two measures of story exposure and reported teaching behaviours, participants were grouped across the four possible combinations of the two measures: high teach-high read; high teach-low read; low teach-high read; and low teach-low read, and reading outcomes over time were compared. Children who had the advantage of both high levels of book reading and of parent teaching outperformed the rest of their peers. The findings suggested that parent teaching will effect early decoding and that story exposure will have a continued affect on developing literacy once these early skills are mastered.

Many parents report teaching letter knowledge to their child, with such instruction found to be predictive of later reading outcomes^[19,21-23]. A positive relationship between letter knowledge and phonological awareness is also described^[24], with better literacy outcomes demonstrated by interventions which explicitly linked phonological activities to letter knowledge^[25]. Children's knowledge of concepts of print is also associated with better reading outcomes^[26].

In their longitudinal New Zealand based study of reading Tunmer, Chapman and Prochnow^[27] found a strong relationship between early literacy skills and later reading outcomes with nearly 50% of the variance in later reading outcomes attributable to what they termed *literate cultural capital* at school entry. *Literate cultural capital* covers a range of HLE features including phonological awareness, letter knowledge, grammatical sensitivity and vocabulary. Limited literate cultural capital can prevent children from accessing the literacy instruction practices of the classroom.

In general, New Zealand home environments are rated very favourably internationally in terms of facilitating children's early literacy development. One of the findings from the Progress in International Reading Literacy Study (PIRLS,

2005/2006)^[28] indicated that New Zealand parents were more likely to engage their child as a preschooler in literacy related activities compared to the other 39 countries which participated in the study (as measured by parental report). However, no data related specifically to children with special needs or children with Down syndrome was collected in this study.

The Home Literacy Environments of children with Down syndrome

While the literature around the HLE is reasonably robust for typically developing, far less is known about the HLE of children with disabilities and no previous investigations have been conducted in this area for New Zealand children with Down syndrome. Researchers suggest the HLE of children with disabilities may not be as rich and supportive of literacy development as that provided to typically developing children. Fitzgerald, Roberts, Pierce and Schuele^[29] investigated the HLE of 3 preschool children with Down syndrome. They found that although the homes contained numerous books and literacy based materials, when compared with the results of Teale^[30] for typically developing children, the literacy-based interactions between the parents and children with Down syndrome were fewer and were largely made up of story reading events. Moreover, the events that did occur tended to be presented in isolated and defined occasions rather than occurring in everyday contexts.

Other comparisons present a similar picture, with parents in the van Bysterveldt et al.^[17] study reportedly reading to their preschool child with Down syndrome for approximately 15 minutes per day, compared to parents in the Rideout, Vandewater and Wartella^[31] study who reported they spent about 40 minutes per day reading with their typically developing preschool child.

Marvin and Mirenda^[32] also found the parents of children with disabilities had much lower literacy expectations and priorities, and engaged in significantly fewer literacy related experiences than those of typically developing children, and Marvin^[33] found that children with multiple disabilities had poorer HLEs than those with single disabilities. However, Marvin^[33] cautioned that there is a need for further investigation as to the levels and type of disability and HLE. This sentiment is echoed by Weikle and Hadadian^[34] in their review of the literature pertaining to literacy environments and development for children with disabilities. The reviewers highlighted the need for research into emergent literacy and the role of the home literacy environment for chil-

dren with disabilities.

Ricci^[35] recently compared parent beliefs about reading and the HLE of 20 preschool and 17 school-aged children with Down syndrome with 18 typically developing children, matched for chronological age with the younger children and for mental age with the older children. Findings suggested parents' beliefs about reading and provision of literacy experiences for children with Down syndrome were more influenced by the child's mental age than their chronological age, which suggests they may be more aligned with the needs of their children than many educational programmes, which are predicated on chronological age. If children with Down syndrome can acquire many of the underlying skills for reading, but on a later schedule than their classmates (as Ricci's^[35] study showed), they may benefit from both earlier and longer exposure to formal literacy experiences than they currently appear to receive. Ironically, the younger children with Down syndrome in Ricci's study were not assessed on measures of emergent literacy because it was assumed the tasks would be too cognitively demanding. Other studies, however, have demonstrated preschool children with Down syndrome have measurable emergent literacy skills and are capable of acquiring these skills before they begin school^[17,36].

Trenholm and Mirenda^[37] investigated the home and community literacy experiences of individuals with Down syndrome. They collected survey data from the parents/caregivers of 224 Canadian individuals with Down syndrome ranging in age from 3 to 42 years. The 105 who were aged between 5 and 13 years form a group comparable in age to the participants in the current study. The parents reported on the literacy experiences of the participants in four main areas: goals, priorities and interest placed on literacy achievement, their child's abilities and experiences with reading and with writing, and the parents' perception of barriers to literacy development. Although no parents ranked learning to read or write as their number one priority for their child, learning to read was identified by over half the respondents as being as one of the three highest priorities for their child aged 5-13 (56% of parents of 5-9 year olds and 62% of parents of 9-13 year olds). However, a lesser priority was given to learning to write. The highest ranking for learning to write was again demonstrated by parents of participants aged 5-13, rated as one of the top three priorities for their child by 18% of parents of 5-9 year olds and 24% of parents of 9-13 year olds. The children demonstrated high levels of interest in acquiring literacy skills with over 70% of 5-13 year olds reported to be 'some-

what' or 'very' interested in learning to read and to write, and over 80% to be interested in drawing.

Approximately half of the parents in the Trenholm and Mirenda^[37] study indicated they believed the prime age for literacy development in children with Down syndrome was between 6 and 12 years old i.e., from the beginning of compulsory schooling. This finding is consistent with the Purcell-Gates^[38] descriptive study, which saw parents increase formal and informal literacy interactions with their child in response to their child entering formal schooling. This suggests they share the predominant 'reading readiness' mind-set of many educational systems. An emergent literacy approach, on the other hand, would encourage parents to prioritise and provide the environment for literacy based experiences and interactions for their child from an earlier age, as well as emphasise the active role of the child in the acquisition of literacy.

It is important to expand our understanding of the HLE of children with Down syndrome in order to inform parents and professionals of relationships between HLE variables and positive literacy outcomes for children with Down syndrome and indicate ways to enhance their HLEs. Investigations can provide evidence to support the development of targeted interventions specifically aimed at facilitating literacy with this population.

The current study adopted an emergent literacy framework to explore key features of the HLE of school-aged children with Down syndrome in New Zealand across three broad themes:

1. What are parents' priorities regarding literacy for their child with Down syndrome?
2. How does the HLE of children with Down syndrome support literacy development? Specifically:
 - i) What are the frequency and duration of literacy interactions?
 - ii) How do parents facilitate and encourage their child's literacy development?
3. How do children with Down syndrome participate in literacy interactions?

Method

Research design

This descriptive study reports survey data gathered via questionnaire on the home literacy environment of children with Down syndrome, completed by parents of participants.

Survey design

A Developing Literacy Questionnaire was modelled on and adapted from the Early Literacy Par-

ent Questionnaire by Boudreau^[2] with permission from the author. It was piloted with six parents of children with Down syndrome and modified in light of their feedback. The final version consisted of 49 questions under the following headings: *Educational Setting; Reading Books; Response to Print; Language Awareness; Interest in Letters; Writing and Television/Computer*^a. Respondents were also invited to make additional comments at the end of the questionnaire. The questions encompassed a number of broad themes including frequency and duration of literacy interactions, other ways parents support and facilitate literacy, parents' priorities for their children at school, and the child's literacy skills. The majority of the items called for binary responses, fill in the blanks or Likert scalar responses that could be quantified. Approximately 20% called for more qualitative descriptive responses. For example, following a question which asked parents to indicate how often they helped their child with their reading, they were asked about the sort of help they gave. Other descriptive questions which were overtly designed to encourage a positive approach to the activity of filling in the questionnaire, were included in response to feedback from the pilot questionnaire, such as "What are some of your child's favourite books?" and "What do you enjoy most about reading with your child?". For the 30 questions assessed using a Likert scale and appropriate for all parents to answer, Chronbach's alpha equalled 0.921. These results are based on the 63% of parents who responded to all 30 questions. However, generalisation to the whole sample is appropriate as no pattern was observed to missing responses and response rates were over 92% for all 30 questions included in the analysis. (A complementary survey completed by participants' teachers was also developed and is reported elsewhere.)

Participant selection

All eligible mainstream and special primary schools in New Zealand (approximately 2,060) were approached via a letter of introduction inviting those with a child with Down syndrome on their school roll to participate in the survey. Initial expressions of interest in the study were

received from responding schools on behalf of 169 children. Schools were sent project information sheets, surveys and consent forms to distribute to parents and teachers and were provided with a stamped self-addressed envelope to return the surveys to the lead researcher. Sixty-five schools subsequently declined to participate. Reasons given for non-participation included school involvement in other projects such as professional development or educational review, teacher's workload, teacher and parent health, and families' domestic circumstances. A further 16 failed to return the survey. Completed surveys were received from parents for 85 children equating to a return rate of 50%. This cohort represents an estimated 15% of the children with Down syndrome in New Zealand primary education (years 1-8)^b.

Participants

The participants were 85 children with Down syndrome (38 girls and 47 boys) aged between 5;4 (y;m) and 14;11 (M = 8;11, SD = 2;6). Criteria for inclusion were a diagnosis of Down syndrome and enrolment in the school programme in years 1-8 (for children aged 5 to 14). Given that fluctuating or compromised health status is prevalent in children with Down syndrome, children were not excluded on the basis of significant ongoing medical concerns, hearing or visual impairment or a diagnosis of additional developmental disabilities.

Participants' mothers/stepmothers made up nearly 90% of respondents. Fathers completed almost 5% of the questionnaires with a further 3.5% completed jointly by parents. The remaining questionnaires were completed by the participants' legal guardians.

The 85 participants came from 55 mainstream schools (64 participants) and 9 special schools (21 participants) based throughout rural and metropolitan New Zealand^c. The schools represented a range of socio-economic levels as indicated by the New Zealand Ministry of Education's decile system^[41]. A school's decile is based on the socio-economic standing of the community from which a school draws its pupils and is based on national census data. Decile 1 schools have the

^a A copy of the survey is available from the first author on request.

^b Although there are no New Zealand national prevalence data for Down syndrome births, Stone^[1] reported stable yearly prevalence data of 1.17 per 1000 births between 1997 and 2003. Mean New Zealand birth rate for the period during which participants were born (1992 to 2001) was 57,799 (SD = 1,305)^[39]. From these data it can be estimated for the purposes of the research that 65-70 children with Down syndrome were born in New Zealand annually during that period and that approximately 575 children with Down syndrome are in school years 1-8 (Children are required to attend school from the age of 6 (Year 1) although they may, and most do, attend from 5).

^c (There are 28 non-residential special schools in New Zealand located in 14 different towns and cities. Sixty-eight percent of the special schools are located in the six largest urban areas^[40].)

highest proportion of students from low socioeconomic communities with decile 10 schools having the lowest proportion of students from low socioeconomic communities. Twenty percent of participants attended low decile schools (decile 1-3), 47% attended middle decile schools (decile 4-7) and 33% attended high decile schools (decile 8-10). Analysis of decile of schools that declined to participate or who failed to return the survey revealed 13% were low decile schools, 68% were middle decile schools, and 19% were high decile schools.

Data analysis and reliability

All coding and data entry was checked by the lead researcher. Additionally an independent researcher coded a randomly selected 20% of the survey returns and checked reliability of data entry and survey interpretation with scores recorded by the lead researcher. Inter-rater reliability was 99.8% with any discrepancies resolved through discussion.

The results presented below represent analyses by descriptive and non-parametric statistics of both the sample as a whole and divided into two age groups: Group 1 (5-8 years; N = 48, M = 7;0, SD = 12.5 m) and Group 2 (9-14 years; N = 37, M = 11;2, SD = 19.2m). The division between the groups was made on the basis that participants aged 5-8 years were typically in classrooms where formal literacy instruction occurred on a regular basis, whereas participants aged 9-14 years were typically in classrooms where the focus was on 'reading for learning' as opposed to learning to read.

Results

Results are presented within three broad themes, for all participants and by age group when group differences are apparent.

Parents' priorities regarding literacy for their child

When asked to report on how important they rated classroom reading instruction for their child in comparison to other classroom activities, 79% of Group 1 parents and 86.4% of Group 2 parents selected classroom reading instruction as either their first or second most important activity. Similarly, when asked to rank skills in order of importance for children to learn at school, an equal proportion of parents in each group (43.2% Group 1; 43.7% Group 2) placed reading in the first position and another approximately 40% in both groups placed it in second ranked position. Parents who rated social skills as the most important area for their child to learn at school (48.6% Group 1; 59.3% Group 2), typically ranked reading and writing in second and third place respectively. Despite the high rankings parents gave to literacy learning at school, not all parents participated in regular discussion about their child's literacy with the teacher or teacher aide. The pattern of response was similar between groups with 63.4 % of Group 1 parents and 74.2% of Group 2 parents reporting they discussed issues relating to their child's literacy at least monthly.

A key measure of a rich HLE is that literacy activities are a source of interest and pleasure for both parent and child. A number of questions in the survey addressed these issues. Notwithstanding their lack of engagement with their child's teacher about their child's learning to read, parents were very clear about the value of reading at home. When asked what they most enjoyed about reading with their child, parents' responses revealed two main themes; 1) social and emotional reasons and 2) seeing their child's achievement and development. Time spent reading together and seeing their child's interest and engagement books was identified by 58% of parents as being what they most enjoyed about reading with their child. The remaining 42% of parents reported their child's speech and language or reading development gave them most pleasure when reading together with their child.

One measure of the emphasis on literacy in the home is the number of books the family owns. The mean and median number of books owned was 50-75 for all children and was 50-75 and 75-100 for parents, with 10% percent of parents and 5% of children owning fewer than ten books, and 42% of parents and 30% of children

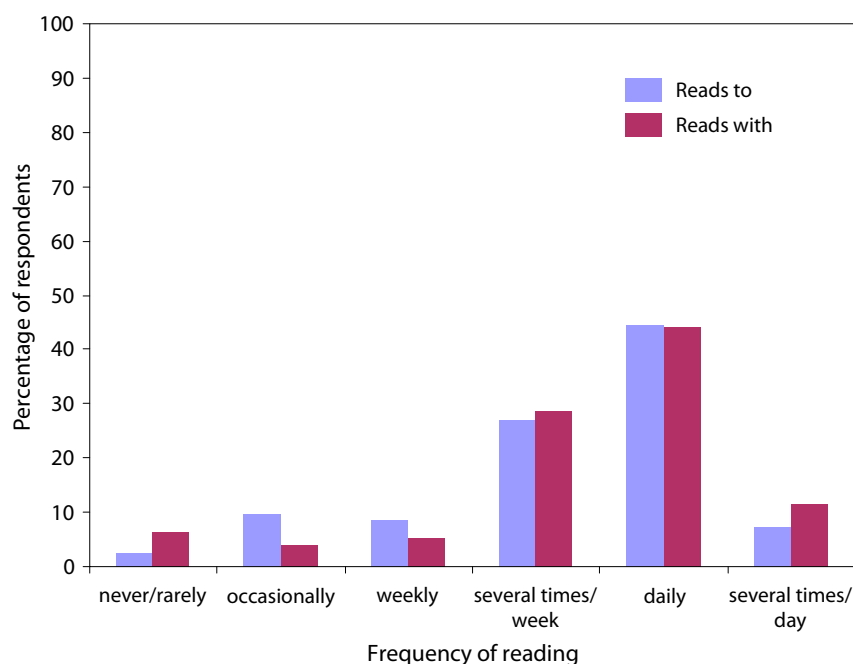


Figure 1 | Frequency of joint reading

owning over 100 books. The 5% of children with the fewest books were all in the younger age group (5-8 years). Eighty-two percent of families reported they received published materials including newspapers and magazines. These numbers are virtually identical to those reported in the PIRLS^[28] report which revealed New Zealand 4th grade children had high numbers of children's book in their homes (36% owned 100+ books, 4% owned <10 books).

The majority of children in the study were introduced to books at a young age, with 66% of parents reporting they began reading together when their child was a baby (i.e. <12 months old) and 11% when their child was 1 year old. However, 22% of children were reported to be aged between 2 and 5 years when their parents began reading with them. Sixty-eight percent of parents reported they had a designated time for joint reading activities with the most commonly reported times being after school and before bed-time.

HLE support for literacy development

Frequency and duration of literacy activities: Reading

When asked about the frequency and duration of reading to their child (parent reads) and with their child (child reads), over 90% of parents reported they read to and/or with their child. Figure 1 shows 48% of these parents were reading together with their child daily and over 10% were reading several times per day. Reading times per week averaged 3.8 hours (SD = 3.02 hours) and ranged from ten minutes to fourteen hours. These figures combine reading for pleasure and reading homework.

Home reading practice was a regular occurrence for almost all participants. Eighty percent of all participants brought books home from school for home reading practice at least weekly, with 48% engaged daily. The median group score for frequency of home reading practice was higher in Group 1 (younger children) than in Group 2 with differences approaching the level of significance [Mann Whitney U = 1089.50, *p* = 0.057]. Although 10.4% of Group 1 children (5-8 year olds) were reported to never have home reading practice, a higher proportion of this group had home reading practice on a regular basis. Eighty-five percent of Group 1 children had home reading practice at least weekly and 58.3% did so daily. By contrast, all children in Group 2 (9-14 year olds) were reported to have home reading practice although for 27% of them this was 'occasional' or 'rare'. Seventy-two percent of Group 2 children had home reading practice at least weekly and 35.1% did so daily. The fre-

Activity	Percentage of Group 1	Percentage of Group 2
Tell child the word/read to the child	39.0	60.0
Prompt/sound out	24.3	34.2
Read together	29.2	0
Keep focused, encourage and praise	4.8	25.7
Point to words	12.1	11.4
Use picture and sign cues	7.3	14.2
Model and support speech clarity and pronunciation	7.3	8.5
Sight words/flash cards	7.3	8.5

Table 1 | Percentage of respondents using techniques to help their child with reading at home

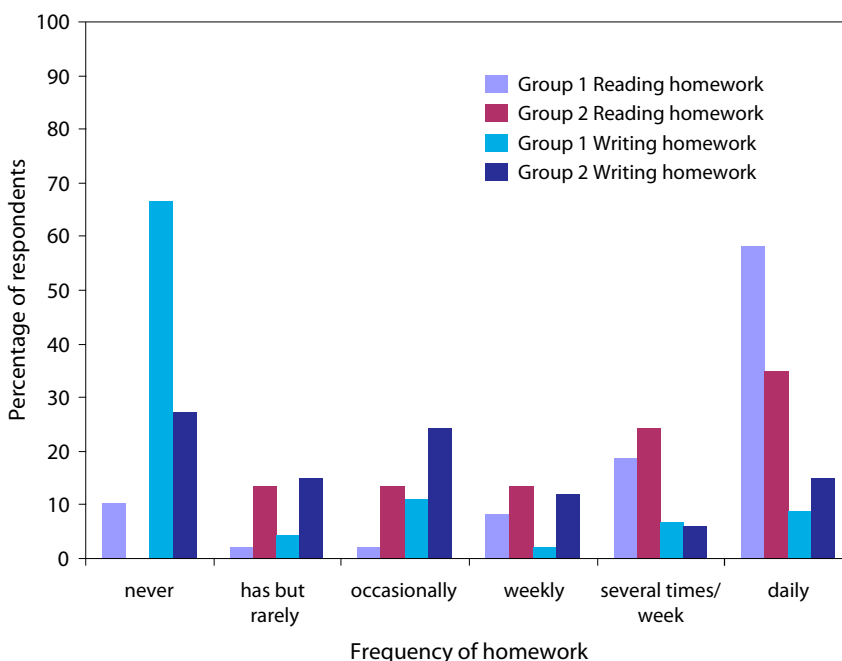


Figure 2 | Frequency of allocated reading and writing homework for participants by group

quency of reading and writing homework is presented in FIGURE 2. Overall, parents reported high levels of reading support for their child with 96% reporting they helped their child with reading, and 62.2% providing help on a daily basis.

Parent support and facilitation of literacy acquisition: Reading

When asked about the kind of help with reading they gave their children, parents' responses fell into eight main categories, with some parents reporting using several of the techniques shown in TABLE 1 to help their child. Many more parents of older children reported using techniques to keep their child focused. More parents of older children also reported reading to their child or telling them the word when reading, whereas more parents of younger children reported using techniques where they read together.

The parents' responses revealed that most were actively involved in teaching their child letter names and sounds on a regular basis, usually during story reading activities. Sixty-seven

Frequency	Drawing		Letters		Words		Stories	
	Group 1	Group 2	Group 1	Group 2	Group 1	Group 2	Group 1	Group 2
Not yet	4.3	0	13.0	0	28.8	2.8	67.3	35.2
Occasionally	13.0	16.6	15.2	20.0	22.2	11.4	13.0	20.0
Weekly	4.3	8.3	6.25	2.8	4.4	2.8	0	5.7
Several times/week	28.2	25.0	17.3	8.5	13.3	22.8	4.3	14.2
Daily	50.0	50.0	47.8	68.5	31.1	60.0	15.2	22.8

Table 2 | Percentage of children engaged in specific writing tasks

percent of Group 1 parents and 57.3% of Group 2 parents reported teaching letter names and sounds when reading together. Correlational analysis, however, demonstrated no relationship between reported measures of frequency of joint reading and the practice of teaching letter names and sounds during joint reading ($r = 0.04, p = 0.75$). Over half of all parents (58%) also commonly incorporated letter knowledge instruction into other activities with their child.

Over half of all parents reported drawing their child’s attention to environmental print such as restaurant and shop names and signs, and street signs at least weekly. Almost 21% of Group 1 parents reported playing language games regularly with their children compared to 32.2% of Group 2 parents. The majority of children were also reported to be regular library users, albeit facilitated by their parents as befits their age. More library activity was reported for older children with 58.3% of Group 1 children and 71.3% of Group 2 children visiting the library at least monthly. One quarter of the younger children were reported to never visit the library compared to 5.7% of older children.

With respect to television, video and DVD viewing habits, parents’ responses indicated wide variation in total viewing times ranging from 0.56 hours to 33.5 hours per week. Mean total viewing time for Group 1 children was 14.1 hours per week (SD = 7.8, range = 0.81 – 31.5), that is 2.01 hours per day. Mean total viewing time for Group 2 children was 14.9 hours per week (SD = 7.2, range = 3.1 – 33.5), that is 2.12 hours per day. The most frequently watched television programmes, reported by over 90% of parents, were cartoons. Many parents reported high levels of video and DVD ownership (for example 30, 100, 200) with over 10% of respondents reporting they had “too many to name”. Most frequently reported titles included cartoon movies and interactive musical shows. Increased total viewing hours was moderately correlated with age for children in Group 2 ($r = 0.46, p = 0.005$) with an estimated increase in total viewing time of 0.18 hours per month of age (2.16 hours per year of age).

When asked whether and how often their child drew, wrote (or attempted to write) letters of the alphabet, words or stories, parents reported

drawing as the most common activity with 50% of both groups drawing daily. Group differences in favour of Group 2 were apparent on reported frequency of writing letters [Mann-Whitney U = 807.00, $p = 0.021$], words [Mann-Whitney U = 398.00, $p < 0.001$], and stories [Mann-Whitney U = 525.00, $p = 0.006$]. Story writing was the least common daily activity with 15.2% of Group 1 children and 22.8% of Group 2 children writing, or attempting to write, stories every day. The majority of Group 1 children (67.3%) and 35.2% of Group 2 children had yet to write or attempt to write stories and a number of children in Group 1 were reported to be not yet engaged in any drawing or writing. The percentage of each group engaged in each activity and the frequency of that activity decreased as the complexity of the activity increased (see TABLE 2).

It is worth noting that a question about tools children used for writing revealed a rich array of writing implements and surfaces was available to all children in the study including a range of pens, pencils, crayons, chalk, paint, paper, and whiteboards.

Parents reported that written homework tasks were less common than home reading practice. Half of all children were reported to ‘never’ have written tasks for homework, with 24% having written tasks for homework ‘weekly’ or more frequently, and 11% engaged in written homework tasks ‘daily’. Significant group differences were apparent [Mann Whitney U = 475.00, $p = 0.004$], with Group 2 children more likely to have regular written homework tasks (see FIGURE 2).

Not surprisingly given the lack of writing homework being assigned, 66% of parents reported they ‘never’ or ‘occasionally’ helped their children with writing; 4% provided help on a ‘daily’ basis. Many parents reported using several techniques to help their child with writing, with 40.5% writing words for their child to copy or trace and 32.4% helping with letters and spelling. Hand over hand support was provided by 24.3% of parents and help with topic discussion provided by 8.1% of parents. Nearly 3% of parents reported providing resources to help with writing. Analysis of the data for all participants revealed small to moderate correlations between the frequency of homework literacy tasks and

Frequency	Comments on pictures		Asks about pictures		Asks about characters or events	
	Group 1	Group 2	Group 1	Group 2	Group 1	Group 2
Not yet	10.6	2.1	23.4	10.8	45.8	24.3
Has but rarely	6.3	5.4	21.2	16.2	8.3	21.6
Occasionally	17.0	24.3	21.2	35.1	16.6	40.5
Few times/story	21.1	21.6	6.3	10.8	12.5	5.4
Often/usually during story	44.6	45.9	27.6	27.0	16.6	8.1

Table 3 | Percentage of children engaged in commenting and questioning behaviours

the frequency of parents' provision of help ($r = 0.57, p < 0.0001$ for reading and $r = 0.32, p = 0.006$ for writing). However, in the case of writing, the correlation was substantially influenced by the large number of children, particularly Group 1 children, receiving no written homework and no help with writing. When data from Group 2 children (who were more likely to have regular written homework tasks) were analysed separately, no relationship was evident between writing homework and writing help for children in Group 2 ($r = 0.29, p = 0.12$).

Approximately half of all New Zealand households have a computer^[42], but home computer ownership was much higher than the national average for survey respondents, with 88.2% of parents reporting they owned a home computer and 81.1% of these reporting their child with Down syndrome had access to it, equating to 71.7% of all children in the study having access to a home computer. Active computer use was more common for older children with 91.1% of Group 2 children compared to 73% of Group 1 children reported to use their home computer. As well as using drawing and word processing programmes, children predominantly played 'educational' games including alphabet and phonics based games, as well as interactive reading, spelling, numeracy and problem solving games. Children were reported to spend an average of 2.51 hours per week on the computer (SD = 1.86, range 0.5 – 8) which equates to just over 20 minutes per day. There were no age group or gender differences.

An important factor influencing the facilitation and encouragement of literacy is parents' awareness of, and ability to cope with, the inevitable challenges. Parents identified a number of challenges associated with reading and writing for their child, with most parents articulating several challenges. Physical and physiological challenges of fine motor skills and control, and vision and hearing were reported by 36.7% and 8.8% of parents respectively. Challenges associated with frustration and behaviour, and attention and motivation were reported by 36.6% of parents and 32.3% reported challenges associated with memory and learning. Speech and

language challenges were reported by 23.5% of parents and 8.8% reported a lack of availability of suitable books. Parents also reported ways they had found to manage these challenges with the majority focusing on addressing the areas of fine motor control and skills, frustration and behaviour, and attention and motivation. Thicker pens, white board markers, magnetic letters and slope boards were offered as adaptations to traditional writing equipment, with computer use suggested as an alternative. Parents emphasised the need for repetition and practice in acquiring reading and writing skills and suggested enlisting the support of family members and teaching support staff to promote this. Specific teaching practices were also identified including visual cues and supports and verbal techniques such as questioning and commenting. Praise and incentives were identified as important in maintaining and promoting children's attention and motivation, along with providing the child with choices from a variety of literacy based activities.

The participation of the child during literacy interactions

As reported earlier, seeing their child's interest in books was a source of pleasure for many parents. When asked to rank their children's interest in books compared to other activities on a six point scale from least favourite (score of 1) to most favourite (score of 6), Group 1 parents more often picked books as a preferred interest than parents of Group 2 children. The median group score was significantly higher in Group 1 (younger children) than in Group 2 [Mann Whitney U = 1103.00, $p = 0.03$].

Despite this reported high level of interest in books however, as TABLE 3 shows, when asked to report on their child's engagement with the pictures, characters and events in a familiar book when reading together, parents reported half of all children (54.1% Group 1; 45.9% Group 2), were 'not yet' or 'rarely' asking about events or characters in the story. Analysis revealed no group differences in the reported frequency of commenting on pictures [Mann-Whitney U = 808.5, $p = 0.57$], asking about pictures [Mann-Whitney U = 742.0, $p = 0.24$], or asking about characters

or events [Mann-Whitney $U = 825.5$, $p = 0.56$] during story reading. Behaviours engaged in by more than 25% of each group are highlighted in boldface type.

A similar picture emerged for engagement with text. Parents were asked to report on their child's engagement with the story line or text when reading familiar books together and whether their child participated in the story telling by saying or reading the next word or line. Many children took a passive role (i.e. 'not yet' or 'rarely' demonstrating the reported behaviours) during joint story reading, with 46.5% of Group 1 and 30.3% of Group 2 not yet or rarely 'saying' the next word or line and 63.0% of Group 1 and 37.8% of Group 2 not yet or rarely 'reading' the next word or line. Group differences approached the level of significance ([Mann-Whitney $U = 550.00$, $p = 0.08$] for 'saying' and [Mann-Whitney $U = 650.50$, $p = 0.053$] for 'reading'), however, although fewer Group 2 children took a passive role compared to their younger peers, a large number were still reported to never or rarely participate in the story telling activity.

When asked about their children's reading abilities, all parents of Group 2 children reported their child was reliably able to identify her or his own name, compared to 62.5% of Group 1 children, with a further 18.7% of Group 1 able to identify their own name 'usually', 14.5% 'often' and 4.1% 'occasionally'.

Similar group differences were apparent on other reading measures. Fifty-seven percent of Group 1 children and 68.7% of Group 2 children were reported to pretend to read by sitting with the book and producing speech similar to the actual story, at least occasionally during joint story reading activities, and nearly half of these children (comprising 25.7% of Group 1 and 31.2% of Group 2) did so often or usually during the story.

Children's ability to read environmental print was also investigated with 97.23% of Group 2 children reportedly able to identify these kinds of words at least 'occasionally' and over 59% able to demonstrate this skill 'daily'. By contrast, 72.3% of Group 1 children could identify these kinds of words at least 'occasionally', and 23.4% could do so on a 'daily' basis. The median group score for frequency of reading environmental print was significantly higher in Group 2 than in Group 1 [Mann Whitney $U = 432.00$, $p < 0.001$]. Parents reported the words most commonly recognised by their child included fast food restaurant and other shop names, food and beverage labels and logos, traffic signs and high frequency words taught at school.

When asked about whether their child read

books independently, parents reported 52.1% of Group 1 and 45.9% of Group 2 children were never or rarely reading independently and 29.1% of Group 1 children and 32% of Group 2 children were reading independently every day. Parents distinguished between their child's independent reading behaviours and their ability to identify their name, environmental print and sight words. Thus although more older children were able to identify these kind of words compared to their younger peers, a Spearman rank order correlation found no significant relationship between reported independent reading and age ($r = 0.015$, $p = 0.89$) for the total sample.

When asked whether their child knew all the letter names and letter sounds, parents reported letter name knowledge to be in advance of letter sound knowledge with 52% of children reported to know all letter names and 28.3% reported to know all letter sounds. No child was reported to have complete letter sound knowledge without complete letter name knowledge although the reverse was true for 21.5% of children. Analysis by age group indicated more older children were reported to know all letter names [Mann-Whitney $U = 464.0$, $p = 0.018$] and letter sounds [Mann-Whitney $U = 381.0$, $p = 0.008$] than their younger peers with 67.6% and 45.1% reported for Group 2 children compared to 39.4% and 14.2% reported for Group 1 children respectively.

Discussion

This descriptive study gathered survey data on the HLE from parents of 85 New Zealand school-aged children with Down syndrome. The survey adopted an emergent literacy framework to explore participants' HLE across three broad themes.

The first of these themes explored the parents' priorities regarding literacy for their child with Down syndrome. The findings of this study suggest most parents place a high value on supporting their children's literacy development. Classroom literacy instruction was identified as a priority by the majority of parents. Additionally, reading and writing skills were ranked amongst the most important skills for their child to learn at school. The homes of the children in this study were generally rich in literacy resources, both for reading and writing experiences.

The mean and median number of books owned by children in the study was similar to the number reported by middle-high SES parents in the Sénéchal^[8] study and consistent with those reported by Mullis et al.^[28] for New Zealand 4th grade children. Mullis et al also reported more books in homes was associated with better reading scores internationally, with substantially

greater reading scores demonstrated by children from homes with high numbers of books. While there was 5% of children (in Group 1) who owned fewer than ten books, it is unlikely, in line with Marvin and Wright^[43] and Trenholm and Miranda^[37], that a lack of literacy resources was a major determiner of the literacy experiences that occurred in the home. There was only one instance where a parent reported both they and their child with Down syndrome owned fewer than 10 books.

Early onset of story reading activities has been associated with improved oral language^[44] in typically developing children and early reading instruction has been associated with increased speech and language skills in young children with Down syndrome^[45]. The majority of children in the study were introduced to books at a young age which is consistent with the findings of other researchers investigating joint reading for typically developing children, with a mean age at the onset of joint reading of 8 months (range: birth to 18 months) reported by DeBaryshe^[44] and 9 months reported by Sénéchal et al.^[8]. However, many parents did not engage with books with their children until shortly before school. Karrass, VanDerventer, and Braungart-Rieker^[46] investigated shared book reading with parents and their typically developing 8 month old infants and reported lower parental stress and higher income differentiated dyads that read together from those that did not. In a study investigating families of children with Down syndrome, Cunningham^[47] reported between a quarter and a third of families were experiencing negative stress, which was most associated with child behaviour problems and low IQ. Thus, while it is conceivable that the parents who reported beginning reading to their child later were those who were experiencing more stress, the late onset of joint reading identified in this study warrants further investigation.

Ricci^[35] reported the literacy environment and experiences of the children with Down syndrome in her study appeared to be most strongly associated with mental age rather than chronological age. Consequently, children (who will go to school on a chronological age schedule) will arrive at school with fewer emergent literacy skills at the onset of formal schooling and formal literacy instruction than their typically developing peers. Consistent with the findings reported by Trenholm and Miranda^[37] and Purcell-Gates^[38], there is a suggestion in the current data that some parents believe learning to read and write begins with the onset of formal schooling and is the responsibility of the teacher, even while they are happy for their children to do the

homework required of them. Clearly this is an area requiring further research.

The second theme investigated features of the HLE, specifically the frequency and duration of literacy interactions and the ways in which parents facilitated and encouraged their child's literacy development.

The findings suggest most parents are actively providing a rich and positive home literacy environment for their children with Down syndrome. Not only were books available to the children in the study, but parent engagement with their child in reading was a frequent and positive experience in most of the homes. Over 90% of parents and children in the study reported reading together, a practice which began early in the child's life for two thirds of the families. Although time spent reading together was extremely variable, the majority of parents reported they had a regular reading time and for 60% of families joint parent child reading was part of their daily routine. Although parents reported joint reading was valued most for its social and emotional benefits, parents were also actively engaging with the print material and encouraged their children's emergent literacy behaviours. In particular, many engaged in the kinds of strategies that have been shown to encourage phonological awareness and speech and language development^[14-18].

Half of all children were engaged in some drawing or writing activities every day, however only 35% of children were reported to write (or attempt to write) words and 15% to write or attempt to write stories. Moreover, some children although they are already at school, have yet to draw or write at all. Additionally, far fewer parents reported regularly helping their child with writing than with reading. Of concern is that many of the parents in the study reported that their children 'never' or 'rarely' brought home writing homework. It must be noted, however, that failure to draw and write did not seem to be because the necessary implements were unavailable.

The relationship between provision of help and the allocation of reading and writing homework prompts further consideration of the role of the school versus the home in encouraging literacy in school-aged children with emergent levels of literacy, given the apparent reliance of many children on work allocated by the school, in class or at home, to develop their writing skills. Homework has been identified as a mechanism for linking home and school^[48] and as part of effective teaching practice. The lack of relationship between allocated writing homework and help with writing for Group 2 children in the current study was unexpected, and suggests there is a need for parents and teachers to work together

to enhance writing skills in children with Down syndrome.

Letter knowledge instruction has been found to be predictive of later reading outcomes for young typically developing children^[19,21-23]. Most parents in the current study reported actively teaching their child letter names and sounds, however, consistent with the findings of Sénéchal and LeFevre^[20], parent teaching of letter names and sounds was not correlated with joint story reading frequency.

Parents also appeared to be taking advantage of a range of other opportunities to encourage literacy. Many children were encouraged to learn from the environmental print of signs and logos and other frequently seen words. Many parents engaged in language games with their children and most children spend time on language rich exposure through TV and other electronic media.

Finally, parents were aware that learning to read and write poses major challenges for their children, and that levels of frustration over fine motor control and difficulties of attention for example, present greater challenges to their children than to many others. Nonetheless, they reported finding ways to stay positive and to work with their children constructively to support their emergent literacy in the ways reported here.

The final theme focused on the ways children with Down syndrome participate during literacy interactions and included the children's engagement with literacy activities and the literacy skills they demonstrated.

Children's literacy interest is an important contributor to reading development and is one of the factors identified by Frijters et al.^[11] as associated with children's phonological awareness, letter knowledge and vocabulary. Children's interest in books was significantly higher in younger children than in their older peers. The classification of children in this study into two groups reflects the typical classroom literacy environment of the children in each age group. As such, the literacy skills and interests of the younger children may be more aligned with the classroom instruction they are receiving. Contrastively older children who face an increasing discrepancy between their literacy skills and their classroom literacy programme may have become disengaged from a literacy programme at school that is incongruent with their skills and interests. A combination of poor skills and infrequent reading practice may also contribute to a lack of engagement with reading activities^[49,50].

The current study reports the frequency of children's spontaneous comments and questions

about the pictures, text, characters and events as measures of their level of active participation during joint story reading. Children were most engaged with literacy tasks which were less cognitively and linguistically demanding, engaging more with pictures than text, commenting more than questioning, and questioning more about pictures than characters or events, with many children reported to take a passive role (i.e. not yet or rarely participating) during joint story reading. However, the child's active participation and engagement during joint story reading is reported to be associated with and predictive of gains in language and literacy skills [e.g. REFS 51,52,53]. Future research directions may include programmes which provide parents with strategies to encourage and promote active involvement during joint book reading by their child with Down syndrome.

As is the case with typically developing children, participant's letter name knowledge was in advance of their letter sound knowledge^[54,55]. Although older children knew significantly more letter names and sounds than their younger peers, fewer than half of the group had complete letter name and sound knowledge. Given the strong link between letter knowledge and reading reported in the literature^[55,56], low levels of letter knowledge are of concern. Buckley et al.^[45] reported some children with Down syndrome were able to use alphabetic strategies to read novel words, however such an ability is contingent on having phoneme-grapheme connections. Single word reading skills were reported to be more advanced in older children than younger children. Additionally, a higher proportion of older children were reported to pretend to read, and to read independently at least occasionally. However, regular independent reading was not correlated with age, with only half of the children reading independently at least weekly. A lack of reading practice has been implicated in delayed fluency and automaticity and reduces the opportunity to acquire the superior vocabulary, declarative knowledge, spelling and reading comprehension associated with increased exposure to print^[49,50,57,58,59].

Limitations

The major limitation of this study is that the data are based on parental report. Parents' answers may portray a more socially desirable response and as such they may have overstated the measures of literacy engagement in the home, and their priorities regarding literacy for their child. Additionally children's reported skills and interests are estimates only and may not be an accurate representation. To counterbalance the

view of the parents, the teachers of these same children were asked a similar set of questions. A report on this data is in preparation. Even with this second data source it may still be that the schools and parents who agreed to participate in the study may have been those for whom literacy was a higher priority.

The study would have been enhanced by the inclusion of a control group of typically developing children. Data from similar studies with typically developing children have been included where appropriate to mitigate this limitation.

Although analysis of the school decile for non-respondents indicated more of these children attended middle decile schools with slightly fewer from both high and low decile schools, the decile distribution is not markedly different

from that of the children included in the study, which therefore may be considered representative of a wider sample. Finally, although the decile of the schools that participants attended is known, no direct information was gathered on families' socio-economic status or on maternal education.

Despite these limitations, the study represents the first attempt to gather systematic data regarding home literacy environments and practices for New Zealand children with Down syndrome. The study provides valuable information for parents and professionals about what literacy environments children with Down syndrome currently experience and may shape directions for future investigation with this population.

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Acknowledgements

This research report is based on a component of the first author's doctoral research under the supervision of the second and third authors. The authors would like to thank parents and caregivers who completed the survey. Thanks also go to Pat Coope, statistical consultant, for support and assistance with statistical analysis.

Author contributions

All authors listed in the byline (van Bysterveldt, Gillon and Foster-Cohen) have made contributions appropriate for assumption of authorship and have agreed to submission of the manuscript.

This paper is an original manuscript and has not been previously published, nor is it under review elsewhere. The project has received ethical clearance from the Human Ethics Committee, University of Canterbury and from The Champion Centre Research Committee. Conflicts of interest have not been identified.

Funding

The first author received financial support for her doctoral research from the following sources: Tertiary Education Commission of New Zealand Top Achiever Doctoral Scholarship; Medical Staffing International-New Zealand Speech-Language Therapists' Association Post-Graduate Award; New Zealand Speech-Language Therapists' Association Research Award. The role of these sponsors was financial support only.

Received: 5 December 2008; Revised version accepted: 4 March 2009; Published online: January 2010