

HOME AND COMMUNITY LITERACY  
EXPERIENCES OF INDIVIDUALS WITH DOWN SYNDROME

by

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A THESIS SUBMITTED IN PARTIAL FULFILLMENT OF  
THE REQUIREMENTS FOR THE DEGREE OF  
MASTER OF ARTS

In

THE FACULTY OF GRADUATE STUDIES

(Department of Educational Psychology and Counselling Psychology, and Special  
Education)

We accept this thesis as conforming

~~to the~~ required standard

THE UNIVERSITY OF BRITISH COLUMBIA

April, 2004

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Title of Thesis: HOME AND COMMUNITY LITERACY  
EXPERIENCE OF INDIVIDUALS WITH  
DOWN SYNDROME

Degree: Master of Arts Year: 2004

Department of Education Psychology and Counselling  
The University of British Columbia

Vancouver, BC Canada

Psychology, and Special Education

## Abstract

Home and community literacy events have a significant impact on literacy development in children. Although there is growing interest about the potential for people with Down syndrome (DS) to become literate, little is known about the literacy events this group experiences. This survey study was conducted to gain a detailed understanding of the home and community literacy experiences of individuals with DS. The data were collected from 224 parent/guardians across Canada to obtain descriptive statistics about the reading and writing experiences of persons with DS in general. The respondents were asked to indicate their literacy goals and priorities for their children with DS, the literacy resources utilized at home and in the community, perceived barriers to literacy attainment, and solutions for alleviating the perceived barriers. The results were grouped according to age when possible, in order to better understand the course of literacy development. Overall, the number of respondents who indicated their children with DS could read and write appeared somewhat higher than in previously published estimates, although the number reporting advanced reading levels was similar to previous reports. The wide range of reading and writing materials observed in use at home appeared to be much greater than the range of materials actually used by children with DS. Relatively few of the parents who read storybooks to their children reported asking higher-level questions, suggesting that some parents might benefit from support in this activity. Many respondents reported using the library and many expressed concerns about the quality and scarcity of literacy programs. The results are discussed with regard to their implications for how parents, caregivers, teachers, and program providers can encourage literacy development in persons with DS, and suggestions for future research are made.

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## ACKNOWLEDGEMENTS

This study could not have been carried out without the support of parents and caregivers who completed the survey and the Down Syndrome Research Foundation. Thank you to all who participated and to Jo Mills, Robert Melrose, Sheryl Dickson, Nimet Tejpur, and Dawn McKenna from DSRF for being so enthusiastic and supportive of the project.

Dr. Pat Mirenda first pointed out the value of this research topic to me and offered encouragement and skilful guidance throughout the entire project. Pat, I greatly appreciated your energy, enthusiasm, and ability to create such a positive research environment. Thank you to Dr Linda Siegel for being on my committee and for making suggestions at the proposal stage, and to Dr. Cay Holbrook for being on my committee and for her insightful comments about the results of the project.

While working on this thesis my thinking about literacy was greatly influenced by my study of Japanese. My warmest thanks to Emi Kamada for introducing me to Japanese, to Eiko Sayama for helping with spoken Japanese, and to Yuko Takada for helping me with written Japanese.

Dedication: To the many children and adults with developmental disabilities who want to learn to read and write. Especially to the adult students I had the good fortune to teach and who inspired me to learn more about reading and writing.



## CHAPTER 1

## Review of the Literature

*Defining Literacy*

Literacy is a complex, multifaceted construct that can not be reduced to a single type of competence that is easy to assess (Olson, 1990). Catts and Kahmi (1995) discussed the convergences and divergences between language and reading, and noted the appeal of Gough and Tunmer's (1986) proposal that reading is best viewed as consisting of two primary components -- decoding and comprehension. Such a view of literacy can accommodate research narrowly focused on decoding, more broadly focused on comprehension, or focused on a combination of the two. This definition is also consistent with Olson's view that the main focus of literacy development should be on helping people learn to read and write in ways that are meaningful to them. A strong emphasis on functionality is also seen in Mirenda and Erickson's (2000) definition of literacy as a "combination of reading and writing. Reading is more precisely defined as silent reading comprehension (i.e. the ability to read a text for a personally or externally imposed purpose and gain understanding from it). . . Writing refers to written composition or the translation of thoughts and words into written text" (p. 351). In this view, the importance of reading and writing subskills such as the ability to sound out unknown words and spell is determined by the contribution they make to understanding and composing text (Mirenda & Erickson, 2000). Thus, it appears that the development of literacy requires both the ability to decode and understand words in various contexts that are meaningful and that further the individual, social, educational, and economic interests of the reader or writer.

Olson (1990) cautioned against conceptualizing literacy too broadly, but acknowledged the crucial role it plays in achieving educational, occupational, and social goals in daily life. Light and Kelford Smith (1993) observed that "literacy skills may take on even greater importance" (p. 10) in the lives of people with disabilities, in that literacy skills "provide a means to bypass many of the severe limitations these individuals experience in daily interactions" (p. 10). Although the importance of literacy in the lives of people with disabilities is increasingly recognized (Craig, 1996; Koppenhaver, Evans, & Yoder, 1991; Light & Kelford Smith, 1993; Marvin & Mirenda, 1993), the similarities and differences in the way individuals with disabilities learn to read and write compared to typically developing readers is not well understood. To understand literacy development in people with disabilities, it is first necessary to have a model that explains how typically developing children learn to read and write.

#### *Reading Acquisition in Typically Developing Readers*

Spear-Swerling and Sternberg (1996) developed a model of reading acquisition on the basis of three broad generalizations drawn from research into reading. First, reading is a developmental process in which the reader progresses through a series of stages or phases that are linked to both "broad changes in cognitive development" (p. 81) and to more specific abilities such as phonological processing. This developmental view is consistent with other well-known stage models (Chall, 1983; Ehri, 1991; Frith, 1985; Gough & Juel, 1991).

Second, efficient phonological processing is crucial to reading acquisition in typically developing readers. Smith, Simmons, and Kameenui's (1998) meta-analysis identified six areas of convergence in the study of phonological awareness: (a) phonological awareness is the specific processing ability that accounts for most of the variance in reading ability for

most children; (b) a reciprocal relationship exists between reading and phonological awareness; (c) phonological awareness is increasingly viewed as a complex construct that is multidimensional and consists of several related but independent abilities; (d) phonological awareness is necessary but not sufficient to develop reading ability; (e) phonological awareness can readily be assessed; and (f) phonological awareness can readily be taught to children.

The third generalization noted by Spear-Swerling and Sternberg (1996) is that emergent literacy is a crucial early stage during which very young readers become fascinated with reading before they are able to identify words. Spear-Swerling and Sternberg used “the road to proficient reading” (p. 77) as a metaphor for reading acquisition in typically developing readers. Starting with emergent literacy, children progress through a series of relatively fixed stages as they undergo developmental changes. They noted that “what constitutes ‘reading’ changes with the age and proficiency level of the reader” (p. 80) and argued that, without a model describing how the typical children learn to read, it is not possible to explain how poor readers diverge from “the road to proficient reading.” Their model differs from other reading models in three significant ways. First, it attempts to extend the account of reading acquisition beyond early reading acquisition. Second, they make a distinction between the phases of controlled word recognition and automatic word recognition. And third, they emphasize an interactive approach that considers how a child’s intrinsic cognitive abilities interact with home and school variables.

#### *Diverging from the Road to Proficient Reading*

Snowling and Gombert (2002) argued that, since the research base regarding literacy development in typically developing readers is quite well established, more effort should be

focused on determining how children with impaired cognitive abilities learn to read, given their greater need for skilled intervention. They suggested that children with learning difficulties are commonly thought to fail to become literate due to low intelligence, despite arguments such as Siegel's (1989) that "there is no evidence that lower IQ scores are causally related to poor reading skills." Children for whom there is no well-established research base regarding literacy include those with general intellectual disabilities, visual impairments, speech-language impairments, and specific developmental disabilities such as Down syndrome (DS). It is this latter group that is of particular interest in this review.

#### *Literacy Development and Down Syndrome*

Spear-Swerling and Sternberg (1996) noted that research supporting the view that visual processing makes the central contribution to reading ability has been superseded by research on the role of phonological processing. Much of the research regarding how people with DS learn to read has focused on sight word reading and phonological processing. In the sections that follow, the research related to these factors will be reviewed briefly.

*Sight word reading.* A number of researchers (e.g., Buckley, 1985, 1995; Greene, 1987; Norris, 1989; Olewein, 1995) have successfully taught young children with DS to read using sight word approaches. One explanation of this success is that visual processing is a relative strength for these individuals and is therefore the preferred modality for reading instruction. Buckley's (1985) study is representative of the research in this area. Using parents as teachers, she developed an ongoing home intervention to explore the hypothesis that teaching reading to very young children with DS would facilitate their language development. She noted that, since the language and reading abilities of the participants in her sample varied greatly, they were quite representative of the population of people with

DS. Participants were 10 children with DS between the ages of 5:1 and 7:0. The age at which the children first spoke ranged from 1:10 to 3:2, and their language development at the time of the study ranged from one child who spoke only 20 single words to others who spoke in 7 to 8 word sentences. Thus, some of the participants were learning to read and speak at the same time, which is quite different from typically developing children who have attained a broad range of language skills by the time they begin to read.

The participants received a highly structured reading program that was delivered by their parents. Instruction consisted of an individualized sight word approach in which the participants were taught the children to match, select, name, and communicate the meaning of pictures and related words. The children had participated in the intervention for three years at the time of Buckley's (1985) report. She observed that one child could match, select, and name pictures only; four children could match 3 or 4 identical words on flashcards; four children had sight word vocabularies of 4 to 70 words; and one child had a sight word vocabulary of 700 words (including inflections) and could read simple books. Buckley also observed that, while two participants often made semantic errors such as reading closed for shut, they never made phonological errors. As an explanation, she hypothesized that the children with DS access meaning directly from the visual form and concluded that mastering print-to-sound relationships is not essential for young children with DS to learn to read. There do not appear to be any reports in the literature other than that of Buckley's of children with DS making semantic rather than phonological errors.

In a later follow-up chapter, Buckley (1995) concluded that the young children with DS who were taught to read in her study using whole word approaches typically benefited in five main ways: (1) single words learned from flashcards soon emerged in the children's

speech; (2) practicing two and three word utterances when reading accelerated the emergence of two and three word utterances in speech; (3) the practice of reading correct sentences lead to the use of function words and to improved grammar and syntax in spoken language; (4) the children who read early achieved higher levels of literacy and linguistic competence in later life; and (5) reading practice improved both phonology and articulation. Buckley argued that instructional approaches that emphasize visual processing draw on the cognitive strengths of children with DS and bypass their cognitive weaknesses.

Subsequent research suggests that Buckley's contentions regarding the limited role phonological awareness plays in the reading of children with DS may be overstated. For example, Cardoso, Michalick, and Pollo (2002) observed that the course of development of phonological awareness in children with DS may differ from normally developing readers. They administered a rhyme detection task, an initial phoneme detection task, and a middle phoneme detection task to readers and nonreaders with DS and to normally developing children. Three training items were presented for each task, followed by 12 experimental items which required the children to match the rhyme, initial phoneme, or middle phoneme to an exemplar. The results suggested that, while rhyme detection *precedes* phoneme detection in normally developing children, it does not appear to do so in children with DS. Nonreaders with DS found all three tasks very difficult, while readers with DS found rhyme detection more difficult than either the initial or the middle phoneme detection tasks. Given this, definitive statements about the role of phonological awareness in beginning readers with DS plays should be made with caution.

*Phonological processing.* Research on the importance of phonological processing in the reading development of children with DS has produced mixed results. Cossu, Rossini,

and Marshall (1993) selected a sample of 10 Italian children with DS with a mean age of 11:4 and matched them for reading ability to a group of typically developing children with a mean age of 7:3. In order to achieve accurate group matching, participants completed two reading assessments. In the first, the children were instructed to read aloud 30 (6-9 letter) regularly stressed and 30 irregularly stressed Italian words. In the second task, the children were instructed to read 40 (4-7 letter) words and 40 nonwords that were constructed by modifying the first letter of each word in the paired list (e.g., bambina and tambina). The two groups were matched such that there were no significant differences for Group, Task, or Group x Task interaction on the assessment tasks.

Participants in the two groups then completed four phonological awareness tasks: phoneme segmentation, phoneme deletion, oral spelling, and phonemic synthesis. In the phoneme segmentation task, subjects were instructed to tap on a table the number of phonemes present in 21 individually presented words (7 each of 2, 3, and 4 phonemes). In the phoneme deletion task, subjects were required to delete the first two phonemes of 20 orally presented words (consisting of 4-8 phonemes each) and then pronounce the remainder of each word. In the oral spelling task, they were presented with 21 words (each with 3, 4, or 5 phonemes) and instructed to spell them aloud as a sequence of letter-sounds. Finally, in the phonemic synthesis task, subjects were presented with 20 words (each with either 4 or 6 phonemes) as a sequence of isolated letter-sounds, and instructed to blend these into the correct word. All tasks were explained verbally and by example during 10 training trials in which correct responses were acknowledged and all errors were corrected.

The participants with DS scored significantly lower than their matched counterparts on all four tasks and, since they could read words as well as their 7-year-old matched

controls, Cossu et al. (1993) concluded that phonological awareness appeared *not* to be an essential prerequisite DS should not focus on phonological awareness, a position that is consistent with Buckley's (1985) suggestion that a sight word approach is best for these individuals. However, several authors have criticized the Cossu et al. (1993) study on a number of counts. Bertleson (1993) noted that the participants with DS group might not have understood the task instructions, and Byrne (1993) argued that the phonological awareness tasks might have been too demanding for their working memory and attention span. Cupples and Iacono (2002) observed that the phonological awareness tasks used by Cossu et al. required the children with DS to blend between 4 to 6 phonemes, even though their digit span abilities ranged from 2 to 4 phonemes. They suggested phonological awareness tasks that took this into account would have yielded different results.

Cupples and Iacono (2002) also noted that there has been a recent shift in the literature regarding the value of phonological instruction for individuals with DS, thanks to a growing body of research that appears to refute Cossu et al.'s (1993) claim that phonological awareness is not a prerequisite for learning to read (e.g., Cardoso-Martins, Michalick, & Pollo, 2002; Cupples & Iacono, 2000; Fowler, Doherty, & Boynton, 1995; Gombert, 2002; Snowling, Hulme, & Mercer, 2002). For example, Cupples and Iacono (2000) argued that the interpretation of the data in the Cossu et al. study is questionable because they treated phonological awareness as an all-or-none phenomenon. The performance of the participants with DS was described by Cossu et al. as a "failure on tests of 'phonological awareness' that occasion little difficulty for most normal children" (p. 133). However, the participants did not score zero on the phonological awareness tasks in Cossu et al., and thus clearly had some abilities in this area. Cupples and Iacono (2000) observed that the minimum level of



phonological awareness associated with acquiring an alphabetic reading system is unknown, and noted that participants' level of accuracy on these tasks in the Cossu et al. study was apparently sufficient for them to acquire some reading skills. They suggested that a correlational design would allow researchers to examine whether the relationship between phonological awareness and reading ability is similar for children with DS and typically developing children.

In fact, Fowler et al. (1995) conducted such a study to examine the relationship between phonological awareness and reading ability in young adults with DS. Fowler et al. administered a test battery that included reading, general intelligence, and phonological awareness measures to 33 young adults with DS, ages 17 to 25. Participants' phonological abilities varied considerably, and their reading levels ranged from kindergarten to grade 6. The word attack measure of the Woodcock Reading Mastery Tests-Revised (WRMT-R; Woodcock, 1987) was used to classify readers as novice (decoded 0-2 pseudowords), emerging (decoded 3-10 pseudowords), developing (decoded 11-29 pseudowords) or skilled (decoded >29 pseudowords). Using this criterion, there were 12 novice, 10 emerging, 6 developing, and 5 skilled readers in the sample. Fowler et al. compared participants' performance on the word attack subtest of the WRMT-R to their performance on the Auditory Analysis Test (Rosner & Simon, 1971) which measures phonemic awareness by assessing the ability to delete phonemes or syllables in the initial, medial, and final position of words. The correlation between these measures was .78,  $p < .001$ , indicating a strong relationship between phonological abilities and reading. No participant scored higher than a grade one reading level without achieving at least 10 correct answers on the phoneme awareness task, and no one scored above a grade three level without achieving at least 20

correct answers on the phoneme awareness task. Fowler et al. concluded that these results are consistent with the view that phonological awareness is necessary but not sufficient for successful decoding, since some participants demonstrating phonemic awareness fell in the lower reading categories. They also found a strong relationship between visual memory and reading ability, and concluded that verbal and visual memory both make important but distinct contributions to the development of reading ability in people with DS.

*Comparison research.* Snowling and Gombert (2002) noted the need for “theoretically motivated interventions” (p. 436) to encourage literacy development in people with DS, and cited Cupples and Iacono’s (2002) intervention study as a promising example. Cupples and Iacono conducted an intervention study to compare what they called an “analytical” approach to reading instruction, which incorporated explicit training in phonological awareness, to a “whole-word” approach, which did not. Participants were seven children with DS between the ages of 8:6 and 11:1 who were randomly assigned to one of the two intervention conditions. Four participants received analytic instruction and three received whole-word instruction. All children were instructed individually for 1 hour per week for 6 weeks. In each training session, participants in the whole-word group were taught five words using a custom-designed computer program. Children progressed through five training steps in each session, with progression to the next step requiring either 80% accuracy or three repetitions of the current step. The training steps consisted of (a) naming pictures, (b) matching written words to pictures, (c) matching written words to spoken words, (d) reading single words, and (e) completing sentences. The protocol for the analytic group was identical except for the five training steps, which consisted of (a) selecting pictures that had identical

rhymes, (b) completing a written word in response to a rhyme, (c) identifying a word's initial sound, (d) blending sounds to form words, and (e) completing sentences.

All participants were assessed pre- and post-intervention on the ability to read both the training words and a list of generalization words. Two children from each group made significant improvements in their ability to read the training words. None of the three children in the whole-word group improved in their ability to read words from the generalization list. In contrast, three of the four children in the analytic group made significant improvements in this regard. Cupples and Iacono (2002) concluded that an analytic instructional approach that emphasizes children phonological awareness skills is preferable for teaching children with DS to read monosyllabic words that have regular spelling-to-sound correspondences.

*School and educational variables.* Spear-Swerling and Sternberg (1996) observed that most of the research on reading acquisition research has focused on the intrinsic abilities of potential readers, and suggested that it would also be beneficial to consider how environmental variables at home and school interact with these intrinsic factors. Several researchers have examined the relationship between literacy and environmental variables in adolescents and young adults with DS. For example, Bochner, Outhred, and Pieterse (2001) investigated two hypotheses to investigate the functional literacy skills of 30 individuals with DS (ages 18 to 36) who lived at home with their families. The first hypothesis was that participants' age would be negatively associated with their literacy abilities, since older participants were likely to have had less access to literacy instruction when they were young. The second hypothesis was that participants' degree of school integration with typical peers would be positively associated with their literacy abilities, since increased levels of

integration were likely to provide increased opportunities to learn to read and write.

Participants were assigned to one of two groups: the *integrated* group consisted of those participants who had spent all or most of their school careers in general education or partially integrated classrooms located in regular schools; and the *segregated* group included those participants who had spent all or most of their time in special schools for students with disabilities. Participants were involved in a structured interview and assessments of both their language and literacy skills during the study.

Bochner et al.'s (2001) analysis of the data indicated that there was a positive relationship between literacy development and age for those participants born after 1970, and between literacy development and integration for those participants in the integrated group. However, they also suggested that integrated placement was not sufficient for the development of literacy since some participants in the integrated group were identified as poor readers. Skilled teaching, well-structured curricula, and home and community support were all identified as additional, important factors contributing to literacy development. In addition, a community milieu in which literacy served both functional and leisure purposes in the daily lives of the participants appeared to be an important contributing factor.

In a related ethnographic study, Kliwer (1998) observed the school literacy experiences of 10 children with DS who were included in regular preschool and elementary classrooms over a 2-year period. The classroom experience for six of the students was described as requiring "conformity to an objectively identified sequence of technical skills or cognitive concepts" (p. 171). Kliwer described these six students as being either completely separated from the literacy community of the regular classroom or limited to participating "in remedial practices that focus on low-level concepts or diminished subskills" (p. 173). In

contrast, the other four students were described as full participants in classroom literacy activities in which “teachers saw worth in symbols and print as a tool for connecting students to the wider classroom community” (p. 173). Like Bochner et al. (2001), Kliever concluded that physical integration in regular classrooms is not sufficient to ensure literacy development in children with DS, and argued for a re-definition of literacy that shifts the focus from the attainment of isolated subskills to literacy as a tool for communication.

### *Summary*

Research on literacy acquisition in individuals with DS has indicated that learning to read and write is a feasible and desirable goal throughout the lifespan. The most effective instructional approaches are not yet definitively determined, but it appears clear that these vary according to a person’s developmental level. There seems to be a growing recognition that both visual memory skills and phonological processing make important but distinct contributions in learning to read. Researchers working with both children and adults appear united in the view that literacy should be conceptualized in ways that are meaningful in the daily lives of people with DS. Finally, it seems clear that educational experiences have a considerable impact on literacy development, although the precise variables that are most relevant have not been clearly identified to date.

Spear-Swerling and Sternberg (1996) observed that a complete account of how children learn to read must include emergent literacy. Although definitions of the concept of emergent literacy vary somewhat, they have in common the view that the home environments of young children play an important role in literacy development. Much is known about the influence of home environments on reading acquisition for typically developing readers, but relatively little is known about the influence of this factor on people with disabilities,

including those with DS. The literature on the impact of home literacy experiences for people with a range of disabilities will be explored in the next section.

### *Home Literacy Experiences*

Research on home literacy practices and their affect on literacy development in people with different types of disabilities can inform educational practice in general (Hodapp & Fidler, 1999). Studies of the home literacy experiences of children with general intellectual disabilities (Marvin, 1994; Marvin & Mirenda, 1993; Marvin & Wright, 1997), severe speech and physical impairments (Light & Kelford Smith, 1993), visual impairments (Craig, 1996, 1999; Stratton, 1996), learning disabilities (Rashid, 2002; Scarborough, Dobrich, & Hager, 1991), and DS (Fitzgerald, Roberts, Pierce, & Schuele, 1995) reveal that individuals in these disability groups both share common literacy experiences and differ in significant ways.

### *Home Literacy Experiences and Children with Intellectual or Other Developmental Disabilities*

Marvin and Mirenda (1993) constructed a survey to investigate the home literacy experiences of three groups of preschool children. Two hundred ninety-one surveys were completed by parents of (a) children considered at risk, (b) children receiving special education services, and (c) children without disabilities. The three groups of children differed significantly with regard to the degree of priority their parents placed on literacy, the ways in which the children were involved in literacy activities at home, parents' estimation of their children's future progress in reading and writing, and parents' future expectations of literacy development. Of the three groups, the parents of children with special education needs assigned the lowest priority to literacy development and had the lowest expectations for progress in reading and writing. However, there was considerable variation among these

parents, and about one-third identified the development of reading or writing as a high priority. Parents of children with special education needs (who were not matched with regard to socioeconomic status) also reported fewer kinds of reading and writing activities in the home.

Marvin and Mirenda (1993) also noted several ways in which children with special education needs and children considered to be at risk were similar. Parents of both groups reported less adult mediation of literacy events, less access to alternative writing instruments, and less use of the library than parents of typically developing children. Children in the two atypical groups were involved in fewer literacy interactions and had fewer opportunities to hear rhymes and poems than did typically developing children. These results resembled the literacy practices of families described by Anderson and Stokes (1984), in which reading and writing were primarily used for functional purposes.

In another survey, Marvin (1994) compared the home literacy experiences of preschool children with single disabilities to those with two or more disabilities. Surveys were completed by 168 parents or guardians of children who were enrolled in early childhood special education programs. Speech-language impairment was the only disability for 79% of the children in the single-disability group. Children in the multiple disability group all had one or more sensory, orthopedic, or intellectual disabilities, in addition to a speech-language impairment. The children's access to print material, frequency of writing activities, opportunity to be read to by adults, and ways of being involved in reading activities with adults were similar for both groups. However, the literacy environments of both groups appeared to be less supportive and less stimulating than those of the typical peers who were involved in the study by Marvin and Mirenda (1993). Fewer than half of the

children in either group were read to daily or encouraged to participate in writing activities weekly. In addition, the parents of children with multiple disabilities were less likely to sit beside their children when reading, encourage their children's attempts to write, or provide a variety of print materials. The priority assigned to reading and writing for the children with multiple disabilities was also low, relative to the children with a single disability.

Marvin and Wright (1997) compared the home literacy experiences of children with speech-language impairments, children with other disabilities, and children without disabilities who were peer models in early childhood special education classrooms. The home literacy survey developed by Marvin and Mirenda (1993) was distributed to parents, and 239 surveys were completed. The results indicated that the children with disabilities were less likely than their nondisabled peers to recognize and copy letters, write or draw on a daily basis, pretend to read or write, or engage in question-answer exchanges when reading or writing. These results replicated the findings of Marvin and Mirenda (1993). Marvin and Wright noted that some survey items also differentiated the two groups of children with disabilities. Items that distinguished children with speech-language impairments were more likely to be linguistic in nature – these children were less likely to listen to oral stories, engage in dialogue about stories being read, ask or answer questions about story events, or have words spelled for them during writing activities. Marvin and Wright suggested that poor literacy and language skills in these children “may be associated more with the lack of meaning they take from ample opportunities to interact with print at home than it is from the lack of exposure” (p.161).



*Home Literacy Experience and Children with Severe Speech and Physical Impairments*

Light and Kelford Smith (1993) compared the literacy experiences of preschoolers with severe speech and physical impairments (SSPI) who used augmentative and alternative communication systems (AAC) and those of a group of typical peers without disabilities. A survey was designed to collect information about the physical, linguistic, and cultural contexts in which literacy events occurred in the home. Data from 30 surveys indicated that the experiences of children in the two groups differed in several fundamental ways, even though their literacy environments were similar and both groups of children were reported to be interested in reading and writing. Children in the SSPI group were less involved in asking questions during story reading and had less opportunity to use print materials or engage in writing activities. The parents of the typical children placed a higher priority on literacy activities than the parents of children in the SSPI group. Light and Kelford concluded that children with SSPI who use AAC systems "may be entering school programs with literacy backgrounds that are quantitatively and qualitatively different" from their peers (p. 21).

In a related retrospective study, Koppenhaver, Evans, and Yoder (1991) examined the home and school literacy experiences of 22 literate adults with SSPI who used AAC. They were interested in finding out from these adults how they learned to read, despite what would appear to be overwhelming odds against their doing so. The participants reported the presence of large amounts of reading and writing materials that were used frequently in various ways in their homes. Other than teachers, mothers were most often cited as being very important influences in helping the participants to learn to read and write. Receiving individual attention and being read to were frequently identified as the most useful types of assistance received. Eight participants specifically mentioned the importance of being able to

see text as it was read out loud to them. Participants also reported more social interaction when reading and writing at home relative to school. The two most frequently reported explanations for participants' successful acquisition of literacy skills were parental support and expectations, and their own perseverance and talent. Koppenhaver et al. concluded that, during their school years, the participants had engaged in the same types of literacy experiences as many nondisabled individuals who are literate. They recommended further research to determine how widely models of typical literacy acquisition apply to individuals with SSPI who use AAC.

#### *Home Literacy and Children with Visual Impairments*

Stratton (1996) reviewed the literature on emergent literacy in order to explore how well the core concepts fit with the learning needs of children with visual impairments. The importance of reading to children; helping them to develop the concept that symbols have specific functions; encouraging emergent writing; and providing rich, supportive literacy environments were identified as four essential concepts related to emergent literacy. Stratton noted that, although the importance of the home environment for emergent literacy is well established, relatively little is known about the home literacy environments of children with visual impairments. The home literacy practices for the small number of children with visual impairments in the studies by Marvin and Mirenda (1993; 7%) and Marvin and Wright (1997; 30%) were not specifically analyzed. However, Craig (1996) sought to build on these studies by examining the impact of reading media and the presence of additional disabilities on parent support for emergent literacy in children with visual impairments. Marvin and Mirenda's (1993) survey instrument was modified in response to comments collected in focus groups of parent of children with visual impairments. Two hundred sixty-four survey

respondents were grouped according to whether their children were print readers, braille readers, or print-braille readers (literacy media variable). They were also grouped according to the presence or absence of disabilities in addition to visual impairment in the children (disability variable). The results indicated that, on average, children in the braille group were read to by adults as often as those in the print and print-braille groups. Craig noted that this is important knowledge, given the strong positive relationship that exists between being read to aloud and future success in reading. Two limitations faced by braille readers were also identified: (a) a relative lack of exposure to writing materials and (b) a relative lack of understanding of the functions that writing serves. Interestingly, learning to read and write was identified by parents of visually impaired children without additional disabilities as their highest priority and by parents of children with additional disabilities as their lowest priority. These results appear consistent with Marvin's (1994) findings that parental priorities and expectations for reading and writing are lower for children with multiple disabilities.

#### *Home Literacy and Reading Disability*

Rashid (2002) observed that the relationship between home literacy environments and the literacy abilities of reading disabled children has received little study. She investigated the relationship between the literacy activities of parents and the academic outcomes of 65 children with reading disabilities. Rashid's analysis indicated that home literacy activities were not significantly associated with the children's academic outcomes but were associated with spelling scores and passage comprehension. The relationship between parental beliefs about their children's future progress and the home literacy environment was not significant, nor was the home literacy environment predictive of children's improvement during a reading intervention.

Scarborough, Dobrich, and Hager (1991) investigated the hypothesis that children who have parents who are infrequent readers "receive less exposure to literacy activities than children whose parents are better readers" (p. 508). Participants were 56 children (who were part of a longitudinal study that followed them from preschool through grade 2) and their 112 biological parents. During the children's preschool years, data were gathered from parents about the frequency of adult reading in the home, the frequency of joint book reading, and the children's interest in books. Thirty-five of the 112 parents were identified as poor readers on the basis of criteria that included their performance on reading tests; 29 of these 35 parents reported that they experienced childhood reading difficulties. On the basis of their reading achievement in grade two, 22 of the children were identified as poor readers and 34 as normally achieving readers. The 22 poor readers met the conventional criteria for having a reading disability.

Scarborough et al. compared the parental responses about their children's early literacy activities to the children's grade 2 reading achievements and concluded that, by the time they entered school, the 22 poor readers had "accumulated substantially less experience with books and reading than those who became better readers" (p. 510). However, Scarborough et al. noted that the mere presence of a parent who was a poor reader did not appear to limit the frequency of either parent-child reading interactions or child-alone reading opportunities. Rather, parental comments about their child's disinterest in reading, plus the finding that the parents both of good and poor readers were equally likely to engage in reading interactions, suggested that other factors may operate in addition to or in combination with parental abilities and attitudes to determine children's early reading experiences. They suggested that "something about these children themselves (rather than their parents) that

may have determined how often they are read to” (p. 509). This echoes the earlier findings of Bell and Harper (1977), who examined and reinterpreted studies of aggression, dependency, moral development, and sex-role development. They argued that, despite the strong tendency in socialization research to explain correlations in terms of parent-to-child directionality (i.e., parent effects), explanations in terms of child-to-parent directionality i.e., child effects) are often equally plausible.

#### *Home Literacy and Children with Down Syndrome*

Almost nothing is known about the relationship between home literacy environments and reading ability in individuals with DS. However, Fitzgerald, Roberts, Pierce and Schuele (1995) conducted an in-depth study that specifically examined the home literacy environments of three children with DS (ages 2:9, 3:1, and 3:10). Trained observers (a) used checklists to record literacy artifacts (i.e., any material with print on it); (b) made tape recordings of parent-child interactions to identify literacy references (i.e., any verbal mentioning of reading or writing); and (c) made field notes to record other literacy events or interactions [i.e., “action sequence[s] involving one or more person in which the production or comprehension of print play[ed] a significant role.” (p. 313)]. Data were analyzed qualitatively from three perspectives to arrive at a description of the home literacy environments. Based on these analyses, Fitzgerald et al. concluded that: (a) although the home environments of the children were print-rich, there were only a modest number of actual literacy events, consisting primarily of storybook reading; (b) two of the three mothers used a highly interactive style during storybook reading, which was conducive to literacy development; and (c) there was some evidence that one mother had lower expectations for her child with DS than for her other, typically developing child.

*Research Problem*

It seems clear that literacy development plays an important role in the lives of people both with and without disabilities, and many factors contribute to the attainment of literacy. People with disabilities often struggle to learn to read and write, and are sometimes viewed as incapable of attaining literacy. A growing body of research indicates that reading and writing are attainable goals for many people with DS, and that they can learn to read in basically the same way as typically developing readers. How to best support literacy development in people with DS remains to be determined by future research. Currently, some educators and researchers have concluded that whole word approaches are most effective, while others argue that analytic approaches that incorporate the explicit teaching of phonological awareness skills hold more promise. Increasingly, a balanced middle position that values the contribution of both approaches appears to hold the most promise.

Research examining literacy development suggests that home and community literacy events are crucial factors. Although there is growing interest about the potential for people with DS to become literate, little is known about the literacy events this group experiences. The purpose of this study was to examine the home and community literacy experiences of individuals with DS in order to gain a detailed understanding of their social and cultural literacy experiences. The findings complement research examining other aspects of literacy development in people with DS and may help frame the efforts of parents, caregivers, teachers, and program providers in encouraging literacy development in individuals with DS.

## CHAPTER 2

## Method

This study was exploratory in nature and investigated the following questions: (1) How high is the priority assigned by parents to developing literacy in people with DS of various ages?, (2) What reading and writing events do people with DS participate in at home and in the community?, (3) How do parents and other adults interact with people with DS during reading and writing activities in the home?, and (4) What are the beliefs and attitudes of parents/guardians toward the development of reading and writing in individuals with DS? Hypotheses related to these questions could not be made because of a lack of previous research in this area.

*Survey Construction*

A 42-item survey was constructed to gather descriptive information about the home and community experiences related to the reading and writing practices of individuals with DS (see Appendix A). The survey was modelled after those used by Light and Kelford-Smith (1993) and Marvin and Mirenda (1993), and consisted of five subsections entitled:

*Identification Information; Literacy Abilities, Goals, and Resources; Reading; Writing; and Progress and Needs.* Survey items were written in checklist and multiple choice formats to facilitate completion in a reasonable amount of time by parents. The face validity of the survey questions was evaluated by two University professors with expertise in reading development and/or special education of individuals with developmental disabilities such as DS. Face validity of the questions was also evaluated by the executive director and the program and services director of the Down Syndrome Research Foundation (DSRF). The questionnaire was edited following these evaluations. In addition, the initial version of the

survey instrument and a feedback form (Appendix B) were completed by five parents of children with DS who are known to the researcher. All parents indicated that they were able to complete the survey in 15-20 minutes. Based on their feedback, additional revisions were made to the survey to remove redundant questions, clarify the wording of questions, and simplify some of the question formats.

#### *Survey Distribution*

Survey packages consisted of a letter of invitation to participate from the executive director of the DSRF (Appendix C), a letter from the researcher explaining the purpose of the research and inviting participation (Appendix D), the survey itself, and a self-addressed stamped envelope. Participants in the survey were eligible to be entered into a lottery for a gift certificate at a local bookstore and a copy of *Teaching Reading to Children with Down Syndrome* by Patricia Oelwein (1995).

The target respondents in this study were parents or guardians of children with DS. A total of 418 potential respondents were identified and contacted in cooperation with the DSRF. Eighty-six questionnaires were distributed to parents who attended the Canadian Down Syndrome Society's 15<sup>th</sup> annual conference in Vancouver, BC in May 2003. An additional 332 questionnaires were mailed to parents or guardians who were either DSRF members or who had registered with the Canadian Population Registry for Individuals with DS. Recipients of the mailed questionnaires received follow-up reminder postcards (Appendix E) one week after the initial mailing.

The return rate was 50% (i.e., 43 out of 86 questionnaires) for attendees at the Canadian Down Syndrome Society's annual conference and 55.4% (i.e., 181 out of 332



questionnaires) for the mailed questionnaires. The overall return rate was 54.3% (i.e., 224 out of 418 questionnaires).

### *Participants*

The demographic characteristics of respondents and their families are summarized in Table 1. The respondents were categorized into five groups, according to the age of the person with DS who was the focus of each questionnaire. The five groups included persons with DS ages (years:months): 0 to 5:0 (18.3%); 5:1 to 9:0 (25.0%); 9:1 to 13:0 (21.8%); 13:1 to 19:0 (15.6%); and 19:1 to 41:11 (18.3%). Gender representation was approximately equal except in the 9:1 to 13:0 group (70.2% males) and the 19:1 to 41:11 group (73.2% males).

For all five groups, 100% of the respondents were parents except in the 19:1 to 41:11 age group, where approximately 5% were guardians or caregivers. In all categories, at least 75% of the respondents were mothers. English was the primary language in 91.7% to 98.3% of the respondents' homes across all five age categories. The reported use of languages other than English ranged from 1.7% to 8.3% and included Cantonese, French, Korean, Mandarin, and Thai.

Respondents' occupational status and educational level were classified using a modification of the Hollingshead Four Factor Index of Social Status (as described in Scheider, 1986). In this modification, scores of 1-9 were assigned to each occupation, with 1 = unemployed and 9 = executives, professionals, or large business owners. Scores of 1 to 11 were assigned with regard to years of education, with 1 = elementary school and 11 = Ph.D. A mean family classification was determined for both occupational status and educational level by calculating the average scores for each variable in two-parent households.

Occupational status was high and homogenous across the five groups. The mean parent occupational category of *skilled worker* (Hollingshead score = 5) occurred in all categories, with the exception of the 19:1 to 41:11 age group, where the mean category was *skilled manual worker* (Hollingshead score = 4). The mean parent educational level across the five groups was also high and homogeneous. The educational level classification of *some university* (Hollingshead score = 6) was observed in all categories, with the exception of the 19:1 to 41:11 age group where the mean educational level was *college* (Hollingshead score = 5).

Questionnaires were returned from diverse Canadian geographic locations. Approximately equal numbers of questionnaires were returned from parents in British Columbia and Ontario; depending on the age category, these accounted for between 78.3% and 89.4% of all returns. Questionnaires were also returned from six other provinces and territories and accounted for between 10.6% and 21.7% of the returns, depending on the age category.

On the survey, respondents were asked to indicate the two main ways their child with DS communicated in the home. They reported that speech use increased as a function of age, while the use of gestures and manual signs decreased. Approximately 90% or more of all individuals with DS except for those in the youngest age group (61.5%) were reported to use speech to communicate. The use of gestures was most frequent in the youngest age group (71.8%) and least frequent in the adult group (48.8%). The use of manual sign language was approximately the same as gestures (69.2%) in the youngest age group but was infrequent in the 13:1 to 19:0 group (10.8%) and in the adult group (2.4%).

Table 1

*Demographic Characteristics of People with Down Syndrome Represented in the Sample (Percentages)*

Age in years: months	Primary Language		<u>M</u> Family		Province			Gender		Respondent			Communication of Person with DS		
	English	Other	Occup.	Educ.	BC	ON	Other	Male	Female	Mother	Father	Parent	Speech	Gesture	Sign
Up to 5:0	92.3	7.7	Skilled Worker	Some Univ.	41.0	41.0	18.0	51.3	48.7	82.1	10.3	7.7	61.5	71.8	69.2
5:1 to 9:0	98.3	1.7	Skilled Worker	Some Univ.	43.1	44.8	12.1	46.6	53.4	84.5	5.2	10.3	89.3	57.1	35.7
9:1 to 13:0	97.9	2.1	Skilled Worker	Some Univ.	51.1	38.3	10.6	70.2	29.8	78.7	10.6	10.6	97.2	59.6	23.4
13:1 to 19:0	91.7	8.3	Skilled Worker	Some Univ.	40.5	37.8	21.7	40.5	49.5	75.0	8.3	16.7	94.6	56.8	10.8
19:1 to 41:11	92.7	7.3	Skilled Manual Worker	College	43.9	36.6	19.5	73.2	26.8	75.6	7.3	12.2	100.0	48.8	2.4

<sup>a</sup>Occupation is the mean across both parents, using the Hollingshead Socio-Economic Status Occupational Factor (as described in Scheider, 1986).

<sup>b</sup>Education is the mean number of years across both parents.

*Data Analysis and Reliability*

Descriptive statistics for the survey data were calculated using the *Statistical Package for the Social Sciences* (SPSS, Inc., 2000). Frequencies and percentages were used to describe the demographic characteristics of participants and their children with DS according to age, sex, education, occupational status, educational level, province of residence, and primary language at home. Means, frequencies, and percentages were also calculated to describe the literacy experiences of individuals with DS. A Pearson product-moment correlation was calculated to examine the relationship between gender and the reported reading abilities of persons with DS. Linear regressions were calculated to examine whether total parent occupation score and/or total parent education score predicted the expected reading/writing abilities of individuals with DS.

The researcher checked intra-rater reliability by recoding 10% of the questionnaires and calculating the percent agreement using the formula:  $\text{agreements} / (\text{agreements} + \text{disagreements}) \times 100$ . Intra-rater reliability was found to be 99.8%. All errors were corrected before analyzing the data.

## CHAPTER 3

## Results

In this chapter, the results of the survey across 224 respondents will be presented in four sections: (a) *Literacy Goals, Interests, and Priorities*; (b) *Reading Abilities and Experiences of Individuals with Down Syndrome*; (c) *Writing Abilities and Experiences of Individuals with Down Syndrome*; and (d) *Resources, Barriers, Needs, and Progress*.

Because of the broad age range (3:3 to 41:11) of the persons with Down syndrome (DS) represented in the surveys, data were analyzed both for the total sample and for five age subgroups. The data are presented for the entire sample except when differences across age groups were apparent, in which case the results are presented according to age subcategories.

*Literacy Goals, Interests, and Priorities**Respondents' Goals for their Children with Down Syndrome*

Respondents were asked to rank from 1 (most important) to 3 (third in importance) the most important goals for their children at the time of the survey. Table 2 summarizes the results by age group, with the goals selected by more than 50% of respondents highlighted in boldface type.

Table 2

*Percentage of Respondents Ranking an Area as a Top 3 Priority for Their Child with Down Syndrome*

Area	Age Group				
	Up to 5:0	5:1 to 9:0	9:1 to 13:0	13:1 to 19:0	19:1 to 41:11
Communication	<b>97.3</b>	<b>91.7</b>	<b>81.1</b>	<b>57.6</b>	<b>64.8</b>
Self-help	<b>77.8</b>	<b>56.3</b>	<b>54.0</b>	<b>66.6</b>	43.1
Making friends	<b>55.5</b>	<b>52.0</b>	32.4	<b>57.6</b>	37.2
Reading	30.5	<b>56.3</b>	<b>62.1</b>	27.3	28.0
Writing	8.4	18.8	24.3	12.2	9.4
Recreational skills	8.4	12.5	18.9	24.2	37.4
Knowledge of the world	5.6	6.3	10.8	12.1	18.6
Vocational skills	0	2.1	8.1	36.4	<b>58.6</b>

Overall, communicating effectively, learning self-help skills, and making friends were the goals most frequently ranked in the top three. Communicating effectively was chosen by the majority of respondents across all age groups, learning self-help skills was chosen by the majority across all except the adult age group, and making friends was chosen by the majority for all except the 9:1 to 13:0 and adult age groups. Learning to read was chosen by 56.3% for the 5:1 to 9:0 group and by 62.1% for the 9:1 to 13:0 group. Less than one-third of respondents ranked learning to read as one of the three most important goals for the other three age groups. The development of vocational skills was ranked as an important

goal by 58.6% of respondents for the adult age group. Across all age groups, less than 25% of respondents ranked learning to write as a high priority goal.

*Interest in Learning to Read and Write*

Although the parent respondents ranked neither learning to read nor learning to write as top priority goals for their children with DS, they did report a high level of interest in reading, writing, and drawing on part of the children. Table 3 presents the percentage of respondents reporting three interest levels (very, somewhat, and not at all) of individuals with DS with regard to reading, writing, and drawing. When the percentage of respondents indicating “very interested” + “somewhat interested” totalled more than 50%, the results are highlighted in boldface type.

Table 3

*Percentage of Respondents Reporting People with Down Syndrome to be Very, Somewhat, and Not at All Interested in Reading, Writing, and Drawing, by Age Group*

Age in years:months	Level of interest	Reading	Writing	Drawing
Up to 5:0	Very interested	<b>48.6</b>	17.9	<b>38.5</b>
	Somewhat interested	<b>21.6</b>	30.8	<b>48.7</b>
	Not at all interested	29.7	51.3	12.8
5:1 to 9:0	Very interested	<b>59.6</b>	<b>20.7</b>	<b>41.4</b>
	Somewhat interested	<b>29.8</b>	<b>50.0</b>	<b>41.4</b>
	Not at all interested	10.5	29.3	17.2
9:1 to 13:0	Very interested	<b>48.9</b>	<b>19.1</b>	<b>23.4</b>
	Somewhat interested	<b>48.9</b>	<b>70.2</b>	<b>59.6</b>
	Not at all interested	2.1	10.6	17.0
13:1 to 19:0	Very interested	<b>59.5</b>	<b>37.8</b>	<b>30.6</b>
	Somewhat interested	<b>37.8</b>	<b>54.1</b>	<b>36.1</b>
	Not at all interested	2.7	8.1	33.3
19:1 to 41:11	Very interested	<b>43.9</b>	<b>43.9</b>	<b>26.8</b>
	Somewhat interested	<b>56.1</b>	<b>51.2</b>	<b>31.7</b>
	Not at all interested	0.0	4.9	41.5

Over 70% of respondents in all age groups indicated that their children with DS were either very or somewhat interested in learning to read. Similarly, over 70% of respondents for all except the youngest age group indicated that their children were very or somewhat



interested in learning to write. For the three youngest age groups, more than 80% of respondents indicated that their children with DS were either very or somewhat interested in drawing, while over 50% of respondents indicated this for the two oldest age groups.

*Priority Given to Learning to Read and Write in School*

Respondents were asked to indicate the priority they believed was given to reading and writing instruction for their children at school and in adulthood. Table 4 summarizes their responses to this question. Percentages in excess of 50% are highlighted in boldface type.

For all age groups, 68% or more of respondents indicated that reading and writing instruction were given either moderate or high priority at school in grades K through 9. Fewer than 50% of respondents reported that reading and writing instruction was given either moderate or high priority in grades 10 through 12. Approximately one-half of respondents whose children with DS were adults reported that reading and writing instruction were moderate or high priorities.

Table 4

*Percentage of Respondents Reporting the Level of Priority Given to Reading and Writing Instruction in School and in Adulthood*

	K-Grade 3		Grade 4-6		Grade 7-9		Grade 10-12		Adulthood	
Age in	High-	Low-	High-	Low-	High-	Low-	High-	Low-	High-	Low-
years:months	mod	very low	mod	very low	mod	very low	mod	very low	mod	very low
Up to 5:0	N/A	N/A								
5:1 to 9:0	<b>69.8</b>	24.5								
9:1 to 13:0	<b>70.0</b>	27.5	<b>71.7</b>	15.2	8.6	2.1				
13:1 to 19:0	<b>75.8</b>	24.3	<b>84.9</b>	9.1	<b>67.7</b>	17.7	29.0	9.7		
19:1 to 41:11	<b>79.5</b>	20.6	<b>89.8</b>	10.3	<b>75.6</b>	24.3	47.3	<b>50.0</b>	<b>51.2</b>	36.6

*Reading Abilities and Experiences of Individuals with Down Syndrome*

Survey results are reported in this section with regard to (a) respondents' estimates of the current reading abilities of their children with DS; (b) reading materials typically used at home by others and by persons with DS; (c) the frequency, duration, and types of support provided during home reading activities by persons with DS, and (d) the community literacy activities of persons with DS.

*Reading Ability Estimates*

Table 5 presents the reported reading ability of individuals with DS according to age. The largest percentages in each age group are highlighted in boldface type. Most children in the youngest age group (75.7%) were reported as unable to read, although 21.6% were able to recognize letters. In the 5:1 to 9:0 age group, approximately one-third (31.1%) of children with DS were reportedly unable to read, while approximately 15% could read simple text or text at a grade 1 level. Children aged 9:1 to 13:0 demonstrated a broad range of abilities, with 28.9% described as reading at a grade 1-2 level. Higher ability levels were reported for the two oldest age groups. In the 13:1 to 19:0 group, approximately 30% of individuals with DS were reported to be reading at either a grade 1-2 or grade 3-4 level. In the adult group, approximately 80% were described as reading between a grade 1 and grade 6 level, with the largest percentage (47.1%) reading at a grade 3-4 level.

*Reading Materials Observed and Used by People with Down Syndrome at Home*

Survey questions were included to identify the reading materials people with DS observed being used by others in the home as well as the materials they themselves used. Table 6 summarizes the results related to both inquiries, with the most frequent results reported by respondents highlighted in boldface type.

Table 5

*Percentage of Respondents Estimating Current Reading Abilities of People with Down Syndrome, by Age Group*

Age in years:months	Does not read	Recognize s letters	25-50 words	Simple text	Grade 1-2	Grade 3-4	Grade 5-6	Grade 7-8	Grade 9-10	Grade 11-12
Up to 5:0	<b>75.7</b>	21.6	2.7	0.0	0.0	0.0	0.0	0.0	0.0	0.0
5:1 to 9:0	28.9	<b>31.1</b>	8.9	26.7	2.2	2.2	0.0	0.0	0.0	0.0
9:1 to 13:0	7.9	7.9	13.2	26.3	<b>28.9</b>	13.2	2.6	0.0	0.0	0.0
13:1 to 19:0	2.9	2.9	8.8	8.8	<b>29.4</b>	<b>29.4</b>	14.7	0.0	0.0	2.9
19:1 to 41:11	0.0	2.9	2.9	5.9	20.6	<b>47.1</b>	14.7	5.9	0.0	0.0

Table 6

*Percentage of Respondents Identifying Reading Materials Used by Others and by Persons with Down Syndrome in the Home*

Reading material	% reporting use at home by family members	% reporting use at home by persons with DS
Magazines	93.7	44.1
Newspapers	92.8	30.6
Catalogues	89.2	41.0
Bills	84.3	3.6
Adult books	83.0	5.0
Computers	83.0	52.7
Newsletters	82.1	13.5
Email/internet	79.8	22.1
Recipes	78.9	29.7
Letters	77.6	30.6
Picture books	75.2	62.3
Storybooks	73.5	66.7
Cheques	73.5	13.5
Notes	64.6	24.8
Schedules	58.7	23.9
Dictionary	56.5	9.9
Comic books	22.9	17.1
Closed captions (TV)	13.5	9.5
Basic education materials	8.1	2.3

Although more than 50% of respondents reported that 16 different types of reading materials were used by family members other than the person with DS at home, only storybooks (66.7%), picture books (62.3%), and computers (52.7%) were reportedly used by more than 50% of persons with DS.

#### *Frequency and Time Spent Reading*

Respondents were asked to indicate how frequently their children with DS read any of the print materials identified in Table 6, how frequently family members read aloud to them, and how much time family members typically spent talking to them about what was read. Table 7 displays the results related to frequency of independent and cooperative reading activities, with the highest percentages highlighted in boldface type.

Table 7

#### *Percentage of Respondents and Frequency of Reading Activities at Home*

Frequency	Person with DS uses print	Family member reads aloud to
	material	person with DS
Many times per day	<b>55.2</b>	24.0
once per day	21.2	<b>28.1</b>
4-5 times per week	10.8	15.2
2-3 times per week	8.5	16.1
0-1 times per week	4.2	16.6

Although the range of materials read by individuals with DS was quite narrow (see Table 6), 55.2% of respondents reported that their children used these materials to read many times per day. An additional 21.2% reported that their children with DS read once per day, and 10.8%

reported a frequency of 4 to 5 times per week (i.e., less than once per day). The frequency with which individuals with DS were read to by others was somewhat less, with 28.1% reportedly read to once daily and 24% read to many times per day. The largest percentage (68.3%) of respondents reported spending less than 15 minutes discussing what was read afterwards.

### *Supporting Reading Activities*

Respondents were asked to indicate the type(s) of reading supports(s) that were provided by family members who read to individuals with DS. Table 8 summarizes these results, with percentages exceeding 50% highlighted in boldface type.

Table 8

*Percentage of Respondents Reporting Specific Types of Supports Provided by Readers to Persons with Down Syndrome*

Type of Reader Support	Percent
Reads text in book to person with DS	<b>67.4</b>
Points to pictures and labels	<b>58.3</b>
Points to words	<b>55.0</b>
Asks person with DS to label pictures	46.8
Asks person with DS to point to pictures	45.9
Asks person with DS what happened in the story	26.6
Asks person with DS what will happen next in the story	26.6
Tells the story in own words	25.2
Asks person with DS why something happened	20.2
Person with DS is not read to	8.7

More than one-half of respondents reported that supports typically involved reading text out loud (67.4%), pointing to pictures and labels (58.3%), and/or pointing to words (55%). More complex types of interactions, such as asking what happened in the story, asking the person with DS to predict what would happen next, and asking why something happened, were each reported by approximately 25% of respondents.

#### *Literacy Activities in the Community*

As an indicator of literacy use in the community, respondents were asked to comment on use of the public or school library by their children with DS. Table 9 summarizes the results, with percentages in excess of 50% highlighted in boldfaced type.



Table 9

*Percentage of Respondents Indicating Library Activities by Persons with Down Syndrome*

Library activity	Percentage
Goes to the library with family	<b>70.9</b>
Borrows books	<b>65.5</b>
Reads at the library	24.7
Borrows CDs/audiotapes	23.3
Initiates going to the library	22.9
Uses computers	22.0
Attends storytelling sessions	15.7
Asks librarian for help	14.8
Goes to the library independently	10.3
Does schoolwork with a friend	5.8
Listens to speakers	4.5
Borrows magazines	4.5
Writes	2.2
Works independently	2.2
Uses the library photo collection	1.3

From an extensive list of potential library activities, only going to the library with family members (70.9%) and borrowing books (65.5%) were identified by the majority of respondents. Several additional activities, including reading, borrowing CDs/audiotapes, initiating going to the library, and using computers, were identified by 20% to 25% of respondents.

*Writing Abilities and Experiences of Individuals with Down Syndrome*

Survey results are reported in this section with regard to (a) respondents' estimates of the current writing abilities of their children with DS; (b) writing materials typically used at home by others and by persons with DS; and (c) the frequency, duration, and types of support provided during home writing activities by persons with DS.

*Writing Ability Estimates*

Table 10 presents the reported writing ability of individuals with DS according to age, not including the 0 to 5:0 age group, in which no individuals were able to write. The largest percentages in each age group are highlighted in boldface type.

Table 10

*Percentage of Respondents Estimating Current Writing Abilities of People with Down Syndrome, by Age Group > 5:0 Years (n = 183)*

Writing ability	Age of Person with DS in years:months			
	5:1 to 9:0	9:1 to 13:0	13:1 to 19:0	19:1 to 41:11
Writes/copies name/familiar words	46.4	<b>69.6</b>	<b>59.5</b>	<b>68.3</b>
Writes in workbooks	25.0	<b>52.2</b>	<b>62.2</b>	46.3
Writes school assignments	7.1	30.4	37.8	34.1
Writes in journal	5.4	30.4	43.2	39.0
Writes email	3.6	8.7	37.8	41.5
Writes simple answers to questions	1.8	30.4	<b>51.4</b>	39.0
Writes notes to relay messages	1.8	15.2	45.9	<b>68.3</b>
Writes lists	1.8	26.1	45.9	<b>65.9</b>
Writes letters	1.8	15.2	37.8	41.5
Writes in time organizer	0.0	8.7	16.2	34.1
Completes forms	0.0	2.2	16.2	34.1
Writes postcards	0.0	4.3	13.5	24.4
Does not write	37.5	4.3	2.7	0.0

As might be expected, the reported ability of individuals with DS with regard to writing tasks increased as a function of age. Many children in the 5:1 to 9:0 age group were reportedly able to write their names or other familiar words (46.4%) or to write in workbooks (25%), but

few engaged in other writing activities. Those in the 9:1 to 13:0 group were reported to have a broader range of writing abilities, with over half able to write or copy their names or familiar words (69.6%) and/or write in workbooks (52.2%). Individuals with DS in the 13:1 to 19:0 age group had an even wider variety of writing skills, the most prevalent of which were the ability to write their names or familiar words (59.5%), write in workbooks (62.2%), and/or write simple answers to questions (51.4%). Those in the adult age group were also reported to display a broad range of writing abilities, although the nature of those abilities changed relative to the other groups. Respondents mentioned functional activities such as making lists (65.9%) and writing notes to relay messages (68.3%) most often, in addition to writing names or other familiar words (68.3%). The ability to participate in school-based writing activities that involved workbooks (46.3%) and writing simple answers to questions (39%) were mentioned less often for the adults.

*Writing and Drawing Materials Observed and Used by People with Down Syndrome at Home*

Two items were included on the survey to determine which writing and drawing materials were used at home by family members of persons with DS home and by persons with DS themselves. As with reading materials, respondents reported that a wide range of writing materials were observed being used in the home.

*Writing materials used by family members in the homes of people with DS.* Table 11 summarizes the survey results related to writing and drawing materials used by family members at home. Percentages over 50% are highlighted in boldface type.

Table 11

*Percentage of Respondents Identifying Writing Materials Used by Family Members in the Home*

Materials/Media	Percentage
Pencil/pen and paper	<b>99.1</b>
Computer	<b>92.4</b>
Crayons, magic markers	<b>83.9</b>
Calculator	<b>76.8</b>
Paintbrushes, paints	<b>56.7</b>
Chalk/chalkboard	43.8
Magnetic/felt letters	27.2
Typewriter	6.7
Does not see writing material used	.9

Use of pencils/pens and paper (99.1%), computers (92.4%), crayons or magic markers (83.9%), calculators (76.8%), and paintbrushes or paints (56.7%) were reported in a majority of the homes of persons with DS.

*Writing materials used by people with DS at home.* Table 12 summarizes the writing materials that were reportedly used by people with DS in their homes. Percentages in excess of 50% are highlighted in boldface type.

Table 12

*Percentage of Respondents Identifying Writing Materials Used by Persons with Down Syndrome in the Home*

Writing Activity	Age in years:months				
	Up to 5:0	5:1 to 9:0	9:1 to 13:0	13:1 to 19:0	19:1 to 41.11
Draws pictures with pencil or marker.	82.1	91.2	78.7	62.2	41.5
Plays with writing toys	48.7	64.9	36.2	24.3	7.3
Chooses writing or drawing activity	43.6	61.4	48.9	40.5	26.8
Writes with magnetic letters	41.0	26.3	12.8	2.7	2.4
Uses calculator	25.6	29.8	46.8	64.9	53.7
Draws using a computer	7.7	42.1	42.6	29.7	7.3
Copies letters or words	5.1	59.6	68.1	81.1	51.2
Practices writing letters of alphabet	2.6	49.1	38.3	32.4	22.0
Grammar or spelling worksheets	0.0	0.0	40.4	51.4	22.0
Writes independently with pens, etc.	0.0	22.8	46.8	62.2	58.5
Writes independently with computer	0.0	8.8	31.9	40.5	51.2
Electronic communication device	0.0	0.0	0.0	5.4	7.3
Tells stories for others to write	0.0	10.5	25.5	29.7	12.2
Does not participate in writing	12.8	7.0	6.4	2.7	2.4

As might be expected from the writing abilities of people with DS described in Table 10, the scope of materials used at home for writing appeared to vary as a function of age. For the youngest age group (i.e., up to 5:0), drawing pictures with a pencil or marker (82.1%) was the only activity reported by the majority of respondents, and the overall scope of materials used was quite narrow. For the 5:1 to 9:0 group, more than half of respondents reported that their children drew pictures with a pencil or marker (91.2%), played with writing toys (64.9%), chose writing or drawing activities (61.4%), and copied letters or words (59.6%). Similarly, a majority of respondents with children in the 9:1 to 13:0 group reported that they drew pictures with a pencil or marker (78.7%) and copied letters or words (68.1%). They also reported a broader scope of activities overall, which likely reflects the changing nature of school tasks and expectations. For example, use of calculators (46.8%); grammar and spelling worksheets (40.4%); and both pens (46.8%) and computers (31.9%) for independent writing were all reported more often for 9:1 to 13:0 year olds than for 5:1 to 9:0 year olds.

Respondents with children in the two oldest age groups also reported a broad range of writing/drawing activities. Adolescents with DS (i.e., those in the 13:1 to 19:0 age group) reportedly drew pictures with pens or markers (62.2%), used calculators (64.9%), copied letters or words (81.1%), completed grammar or spelling worksheets (51.4%), and wrote independently with pens (62.2%). Not surprisingly, those in the adult (i.e., 19:1 to 41:11) age group engaged in more “functional” than school-based activities, including using calculators (53.7%), copying letters or words (51.2%), and using pens (58.5%) and/or computers (51.2%) to write independently.

*Frequency and Time Spent Engaged in Writing/Drawing Activities*

Respondents were asked to indicate how frequently and for how long their children with DS typically used any of the writing materials identified in Table 12.

*Frequency of writing/drawing activities.* Table 13 displays the results related to frequency, with the highest percentages highlighted in boldface type.

Table 13

*Percentage of Respondents and Frequency of Writing or Drawing Activities by Persons with Down Syndrome at Home*

Frequency of writing by person with DS	Percentage
Many times per day	<b>28.6</b>
Once per day	<b>17.4</b>
4 to 5 times per week	23.7
2 to 3 times per week	19.2
0 to 1 time per week	10.7

Forty-six percent of respondents reported that their children with DS were involved in writing activities at once per day, and approximately 30% reported that these activities occurred between 0 to 3 times per week.

*Duration of writing/drawing activities.* Table 14 displays the results related to the typical duration of writing/drawing activities at home by persons with DS, with the highest percentages highlighted in boldface type.



Table 14

*Percentage of Respondents and Typical Duration of Writing/Drawing Activities by People with Down Syndrome at Home*

Typical duration of writing/drawing activities	Percentage
Less than 15 minutes	<b>46.8</b>
15 to 30 minutes	<b>32.9</b>
30 to 60 minutes	9.7
More than 60 minutes	4.6
Not applicable	6.0

Almost half (46.8%) of respondents indicated that their children with DS typically wrote or drew for less than 15 minutes at a time. An additional 32.9% reported durations of between 15 to 30 minutes for these activities.

#### *Supporting Writing/Drawing Activities*

Respondents were asked to indicate the type(s) of writing/drawing supports(s) that were provided by family members to individuals with DS. Table 15 summarizes these results, with percentages exceeding 50% highlighted in boldface type.

Table 15

*Percentage of Respondents Reporting Specific Types of Writing Supports Provided to Persons with Down Syndrome*

Supporting activity	Age of person with Down Syndrome in years:months				
	Up to 5:0	5:1 to 9:0	9:1 to 13:0	13:1 to 19:0	19:1 to 41:11
Encourages person with DS to write more	<b>89.7</b>	<b>72.4</b>	<b>78.7</b>	<b>59.5</b>	43.9
Comments on writing/drawing	<b>79.5</b>	<b>86.2</b>	<b>74.5</b>	<b>56.8</b>	46.3
Provides hand-over-hand guidance	<b>76.9</b>	<b>62.1</b>	31.9	13.5	2.4
Positions writing instrument for person with DS	<b>59.0</b>	<b>50.0</b>	25.5	16.2	0.0
Imitates or copies person with DS	48.7	31.0	27.7	10.8	19.5
Writes/draws a model	41.0	<b>63.8</b>	<b>68.1</b>	37.8	39.0
Sits silently and watches	28.2	27.6	31.9	24.3	22.0
Tells person with DS what to write	20.5	27.6	31.9	21.6	7.3
Spells words aloud for person with DS	12.8	34.5	<b>63.8</b>	<b>62.2</b>	<b>51.2</b>
Answers questions	7.7	25.9	46.8	<b>51.4</b>	<b>56.1</b>
Directs person with DS to a model	2.6	3.4	14.9	27.0	17.1
No one writes with person with DS	0.0	0.0	4.3	10.8	19.5

High percentages of respondents for all age groups except adults reported that family members typically encouraged persons with DS to write more and commented on their writing/drawing at home. A majority of respondents with children in the youngest and the 5:1 to 9:0 age groups also indicated that someone often provided hand-over-hand guidance and/or assisted the person with DS to position a writing instrument properly. A majority of respondents for the three oldest age groups (i.e., ages 9:1 to 13:0 and older) reported spelling words out loud for their children, and those with adolescent or adult children reported that they answered questions during writing activities as well.

#### *Resources, Barriers, Needs, and Progress*

In order to gather data about the perceived literacy needs and progress of persons with DS, respondents were asked to (a) indicate recent utilization of community literacy resources, (b) identify barriers to literacy, (c) identify what they believed would constitute an effective literacy intervention for their child, (d) estimate the age at which people with DS in general are likely to make the most progress with regard to reading and writing; and (e) estimate their child's past and future progress with regard to literacy development.

#### *Utilization of Community Resources*

Table 16 summarizes the percentage of respondents who indicated that they contacted specific literacy resources on behalf their children with DS within 6 months prior to survey completion.

Table 16

*Percentage of Respondents and Literacy Resources Contacted Within the 6 Months Prior to Survey Completion (n = 224)*

Literacy resource	Percentage
Library -- general collection	32.2
No resources contacted	30.8
Public librarian	29.9
School librarian	24.8
Private literacy tutor	7.9
Continuing education program	7.0
Peer literacy tutor	5.1
Free literacy program	4.2
Fee-for-service program	2.8
Literacy BC	1.9
Library -- adult basic education collection	1.4

One-quarter to one-third of respondents indicated that they had contacted a school or public librarian and/or had utilized the general library collection within the last 6 months in regard to their child's literacy development. Almost one-third (30.8%) also indicated that they had not contacted any literacy resources. In contrast, fewer than 10% reported that they had contacted or utilized either private or peer literacy tutors, continuing education programs, free or fee-for-service literacy programs, Literacy BC, or the adult basic education collection at a library.

*Barriers to Literacy Development*

Respondents were also asked to identify perceived barriers to their children's literacy development from a list of 15 possible barriers, with the option of adding to the list if necessary. Table 17 summarizes the results related to literacy barriers.

Table 17

*Percentage of Respondents Identifying Specific Barriers to Literacy Development*

Barrier	Percentage
Lack of literacy programs	19.0
Expectations in literacy programs are too low	19.0
Lack of information about literacy programs	18.5
Person with DS is not interested in reading or writing	17.1
Lack of knowledge by others about reading and writing	12.8
Too many other interests by person with DS	11.8
Family members do not have time to join in literacy activities	11.4
Literacy programs are too expensive	6.6
Literacy program content is too easy or too hard	4.7
Transportation issues that prevent attendance at literacy programs	4.3
Literacy program expectations are too high	4.3
Literacy materials are too expensive	2.8
Literacy programs are too short	2.8
Time between literacy programs is too long	2.4
Lack of books	.9

Seven of the 15 barriers listed on the survey were chosen by 10% or more of respondents. Given the sample size, the 10% cut-off point indicates that approximately 20 or more respondents identified the barrier as significant. A lack of literacy programs (19.0%), low expectations in existing programs (19.0%), and lack of information about programs (18.5%) were the three most frequently mentioned barriers. Lack of interest in reading and writing by the person with DS (17.1%), lack of knowledge about reading and writing by others (12.8%), too many competing interests for the person with DS (11.8%), and lack of time by family members (11.4%) were the also selected by more than 10% of respondents.

*Interventions Needed for Literacy Development*

Respondents were asked to indicate which interventions they believed would be most helpful for improving the reading and writing abilities of their children with DS. The results are summarized in Table 18.

Table 18

*Percentage of Respondents Indicating the Need for Specific Interventions to Improve Reading and Writing in Persons with Down Syndrome*

Intervention	Percentage
Literacy program with class 3 or more times per week	41.1
Parent training in teaching reading	35.4
Private tutor	33.5
Parent training in teaching writing	29.7
Peer tutor	20.6
Suggestions from current teacher	20.6
Literacy program with class 1-2 times per week	17.7

Two-thirds of respondents indicated that parent training in teaching reading (35.4%) and/or writing (29.7%) would be helpful interventions. In addition, almost two-thirds indicated that literacy programs convened either 1 to 2 times per week (17.7%) or 3 or more times per week (41.1%) would be helpful. Private tutoring (33.5%) and/or peer tutoring (20.6%) were also selected by a majority of respondents. Receiving suggestions from their child's current teacher was identified as a potentially helpful intervention by 20.6% of respondents

*Estimate of Most Literacy Progress in General*

The survey included an item in which respondents were asked to indicate the age(s) at which they believed that persons with DS were likely to make the most progress in learning to read and write. The results are summarized in Table 19.

Table 19

*Percentage of Respondents Estimating the Age(s) at Which People with Down Syndrome Make the Most Progress in Learning to Read and Write*

Age(s) in years of most progress	Reading	Writing
0-5	20.5	15.2
6-12	<b>55.8</b>	<b>48.0</b>
13-19	30.2	36.8
20-25	9.3	9.8
26 or older	3.7	4.4
Do not know	27.0	30.4

The age range from 6 to 12 was selected most often by respondents for both reading (55.8%) and writing (48%). Approximately one-third indicated that they believed the most progress would be made by people with DS between 13 to 19 years old age in reading (32%) and writing (36.8%). Less than 10% felt the optimum progress would occur during the adult years, and more than one-quarter of respondents indicated that they did not know the answer to this question.

*Estimated Past and Future Progress in Reading, Writing, and Drawing*

*Past progress.* Respondents were asked to estimate the amount of progress made by their child with DS in reading, writing, and drawing during the preceding year. Table 20 summarizes their responses.



Table 20

*Percentage of Respondents Estimating Reading, Writing, and Drawing Progress of People with Down Syndrome During the Preceding Year*

Age in years:months	Reading		Writing		Drawing	
	High to	No to little	High to	No to little	High to	No to little
	moderate progress	progress	moderate progress	progress	moderate progress	progress
Up to 5:0	19.4	80.6	11.4	88.6	43.2	56.8
5:1-9:0	43.8	56.2	<b>52.6</b>	47.4	<b>62.0</b>	38.0
9:1-13:0	<b>53.2</b>	46.8	<b>52.2</b>	47.8	35.6	64.4
13:1-19:0	<b>67.5</b>	32.5	<b>61.1</b>	38.9	37.8	62.2
19:1-41:11	38.4	61.6	33.3	66.7	21.6	78.4

For all but the adult age group, estimations of reading progress progressively increased as a function of age. While only 19.4% of respondents for the 5:0 or younger age group believed that their children had made moderate to high progress in the past year, this percentage increased gradually to 67.5% for the adolescent age group. However, the percentage of respondents estimating moderate to high progress in reading ability for the adult group was only 38.4%, almost 30 percentage points less than for the 13:1 to 19:0 group.

The pattern reported for progress in writing was similar to that reported for reading. While only 11.4% of respondents for children in the youngest age group believed that they had made moderate to high writing progress in the past year, this percentage increased to 61.6% for the adolescent age group. Again, the number of respondents estimating moderate to high writing progress in adults (38.4%) was approximately 30 percentage points lower than for the preceding age group.

Reported progress in drawing did not resemble the patterns for reading and writing. Fewer than 45% of respondents reported either a moderate or high level of progress in drawing for persons with DS in all except the 5:1 to 9:0 age group (62%). Conversely, 56% or more of respondents with children in all but this age group reported no or little progress with regard to drawing over the preceding year.

*Future progress.* Respondents were also asked to estimate their expectations with regard to the future reading and writing abilities of their children with DS. Table 21 summarizes the highest expectations identified by the respondents, arranged in the order of highest to lowest expectations.

Table 21

*Percentage of Respondents Estimating Future Reading and Writing Abilities of People with Down Syndrome*

Highest expected reading and writing abilities	Percentage
Will compete in a college or classroom	15.1
Will be able to read newspapers, magazines, and/or novels	<b>50.0</b>
Will be able to write letters and stories	<b>55.5</b>
Will be able to read simple text and do basic writing	22.9
Will read and spell between 25 and 50 sight words	4.1
Will recognize fewer than 25 sight words	1.4
Will recognize the letters of the alphabet	2.3
Will not be able to read or write	1.4

Half of the respondents indicated that they expected their children with DS to be able to read newspapers, magazines, and/or novels. In addition, 55% expected them to be able to write letters and stories. An additional 15.1% believed that their children with DS would be able to read and write sufficiently to be competitive in a college or university classroom. Only 3.7% believed that their children would not be able to read at least some sight words.

*Correlations*

A Pearson product-moment correlation was calculated to examine the relationship between gender of individuals with DS and their reported reading abilities. A significant correlation was found,  $r = -.28$ ,  $p < .0001$ . Table 22 displays the details of this analysis across all age groups.

Table 22

*Percentage of Persons with DS and Reported Reading Ability by Gender*

Reading ability	Gender	
	Males (n = 126)	Females (n = 98)
Does not read	16.4	<b>35.0</b>
Recognizes letters of alphabet	11.8	<b>17.5</b>
Recognizes 25-50 sight words	7.3	7.5
Reads simple texts	<b>16.4</b>	11.3
Reads grade 1-2	15.5	15.0
Reads grade 3-4	<b>21.8</b>	10.0
Reads grade 5-6	<b>8.2</b>	3.8
Reads grade 7-8	<b>1.8</b>	.0
Reads grade 11-12	<b>.9</b>	.0

Table 22 indicates that, overall, males were reported to be reading at higher levels than females. Approximately twice as many females (35%) were reported being “unable to read,” compared to males (16.4%). Conversely, approximately 61.9% of males were reported to be able to read simple texts or to read within the grade 1 to grade 6 range, compared to 40.1% of females. The number of respondents reporting that persons with DS either recognized letters of the alphabet or recognized 25-50 sight words was approximately equal for males (19.1%) and females (25%).

*Regressions*

Linear regressions were calculated to examine whether total parent occupation score and/or total parent education score predicted parents' expectations of the future reading and/or writing abilities of their children with DS. The total parent education score was determined by adding the education level score for each respondent and his/her spouse, as reported on an 11-point on which 1 = elementary school and 11 = Ph.D. The total parent occupation score was determined by adding scores of the respondent and his/her spouse using a modification of the Hollingshead Socio-Economic Status Occupational Factor scale (as described in Scheider, 1986). Table 23 displays the results of these analyses.

Table 23

*Regressions for Parent Occupation/Education and Predicted Reading/Writing Abilities of Persons with DS*

Predictor	Future reading ability	Future writing ability
Mother + father occupation score	R square = .003, p = .48	R square = .001, p = .77
Mother + father education score	R square = .014, p = .12	R square = .014, p = .15

None of the regressions were significant, indicating that neither total family occupation nor total family education predicted parent expectations in this regard.

## CHAPTER 4

## Discussion

The aim of this survey research was to gather descriptive data about the home and community literacy experiences of children and adults with DS in order to gain a better understanding of how these individuals learn to read and write. The findings of this study provide a basis for making comparisons with other disability groups and normally developing readers. Survey items were designed to gather data in the following categories: (a) *Reading Abilities and Experiences of Individuals with Down Syndrome*; (b) *Writing Abilities and Experiences of Individuals with Down Syndrome*; (c) *Literacy Goals, Interests, and Priorities* and (d) *Resources, Barriers, Needs, and Progress*. The results in each category will be discussed in the sections that follow.

*Reading Abilities and Experiences of Individuals with Down Syndrome*

Survey questions were asked to determine (a) respondents' estimates of the current reading abilities of their children with DS; (b) the reading materials typically used at home by others and by persons with DS; (c) the frequency, duration, and types of support provided during home reading activities by persons with DS, and (d) the community literacy activities of persons with DS.

*Estimated Reading Ability*

Chall's (1983) developmental model of reading provides a useful frame within which to discuss the results related to the reading abilities of individuals with DS. The choice of this model as a point of reference is especially relevant for two reasons. First, Chall's account of reading development across the lifespan provides benchmarks for discussing the estimated reading abilities in this study. Second, Chall's model serves as a counterpoint to those

proposed by Buckley (1995) and Oelwein (1995), whose views about teaching individuals with DS to read have been widely disseminated to parents and teachers. Chall proposed that learning to read involves progressing through a series of hierarchical stages and that the progress through these stages is determined by the interaction between individual and environmental factors. During stage 0 (ages 6 months to 6 years), the child “pretends” to read, retells a story after being read to, names letters of the alphabet, and plays with reading and writing materials. In stage 1 (ages 6 and 7 years), the child learns to associate letters and letter combinations with the sounds they represent, begins to decode simple words, and reads simple texts. During stage 2 (ages 7 and 8 years), basic reading skills are consolidated and reading fluency increases. Collectively, the general focus in the first three stages can be thought of as “learning to read.” The transition to stage 3 usually begins in grade 4, and this stage is not completely traversed until the high school years. In a sense, this is a “watershed” stage and is especially significant because it requires readers to shift from learning to read to “reading to learn.” Chall observed that readers who do not make this shift successfully are often considered functionally illiterate, with reading abilities that are limited to familiar materials that do not extend beyond the person’s existing knowledge and vocabulary.

Within Chall’s stage descriptions, it is interesting to estimate how many individuals with DS in the present study appeared to make the transition to the “reading to learn” stage (i.e., at least a grade 4 reading ability) successfully. Overall, the findings suggest that this occurred for approximately 15% of adolescents and adults with DS and that, in general, children with DS lag far behind their typically developing peers at all reading levels. Only 5% of the 5:1 to 9:0 year age group and approximately 50% of the 9:1 to 13:0 year age group were estimated to read between school grades 1 to 4. These estimates are generally consistent

with previous estimates found in the small body of research concerned with reading achievement in children with DS. Buckley (1985) discussed case studies of children and adults where reading ability was especially notable, and estimated that about 40% of adolescents and adults with DS have at least "some" reading ability. Oelwein (1995) described several very small pilot studies of reading interventions in which children with DS achieved reading levels in the range of grades 1 to 4. The reading abilities of 33 adolescents and adults with DS that were reported in a more extensive study by Fowler et al. (1995) are also congruent with these estimates. Fowler et al. assessed reading achievement using the word attack, word identification, and passage comprehension subtests of the WRMT-R (Woodcock, 1987), and reported that approximately 35% of their participants were assessed at lower than grade 1, 50% were between grades 1 to 4, and 15% were at grade 5 or higher with regard to reading ability. Overall, it appears that, although substantial numbers of individuals with DS learn to read at some level, relatively few make the transition to Chall's stage of "reading to learn." Of course, these reading ability estimates must be interpreted with caution, since the data was reported by their parents and grade level definitions were not provided in the survey.

A Pearson product-moment correlation was calculated to examine the relationship between gender of individuals with DS and their reported reading abilities. A significant correlation was found,  $r = -.28$ ,  $p < .0001$ , indicating a moderate relationship in this regard. This is generally consistent with the results of a previous study of academic achievement in 117 children with DS between the ages of 6 to 14 years (Sloper, Cunningham, Turner, & Knussen, 1990). They calculated a stepwise regression and found that, while mental age



accounted for 62.5% of the variance in their data, gender accounted for an additional 5 %, approximately.

In the present study, males appeared to be reading at higher levels than females. The data in Table 35 indicates that approximately twice as many females (35%) were reported being “unable to read,” compared to males (16.4%). Conversely, approximately 61.9% of males were reported to be able to read simple texts or to read within the grade 1 to grade 6 range, compared to 40.1% of females.

#### *Future Reading Expectations*

The finding that approximately 15% of respondents expected their children with DS would be able to compete at the college or university level is interesting, since it is consistent with the approximately 15% of adolescents and adults who were reported to be able to read at a grade 5 or 6 level in both this study and in that of Fowler et al. (1995). However, these findings suggest that many of the approximately 50% of respondents who expect their child to be able to read magazines, newspapers, and/or novels and to be able to write letters and stories (Table 20) may be underestimating the demands of these literacy tasks. Typically, magazines, newspapers, novels, and so forth require reading ability in the “reading to learn” range (i.e., grade 4 or above), which may not occur for a large number of these individuals. This raises questions about the relationship between literacy goals, priorities, and expectations, which will be discussed in a subsequent section.

Overall, the average occupational status of respondents in the present study was *skilled worker*, with the exception of the oldest age group. Similarly, the average educational attainment reported was *some university*, with the exception of the oldest group. To examine whether parents’ occupational status or educational level predicted their expectations of the

future reading and/or writing abilities of their children with DS, linear regressions were calculated. Neither parent occupation,  $R^2 = .003$ ,  $p = .48$ , nor parent education,  $R^2 = .014$ ,  $p = .12$ , predicted respondents' expectations of the future reading abilities. Similarly, neither parent occupation,  $R^2 = .001$ ,  $p = .77$ , nor parent education,  $R^2 = .014$ ,  $p = .15$  predicted respondents' expectations of the writing abilities of their children.

*Reading Materials, Reading Frequency, and Reader Support*

*Reading materials.* A wide variety of reading material was reportedly used by family members of persons with DS at home, a finding that is congruent with Marvin and Wright's (1997) suggestion that lack of exposure to print materials is unlikely to be a major factor limiting the reading and writing abilities of many people with disabilities. However, although the reported level of exposure to reading materials used by others was quite broad, the breadth of reading materials actually used at home by people with DS themselves was quite narrow. Compared to the 16 out of 19 print items that were reportedly used by 50% or more of respondents in their homes, only computers, storybooks, and picture books were reported to be actually used by the majority of individuals with DS. This suggests that, although a print-rich environment may be desirable, it is not sufficient to ensure that a wide range of reading materials are actually read by individuals with disabilities.

*Reading frequency.* Not only was the range of reading materials used by others at home quite broad, more than 75% of respondents reported that their children with DS read once or more per day. This positive finding was somewhat offset by the approximately 25% of respondents who reported that their child read less than once a day. Similarly, although more than 50% of respondents reported that they read out loud to their child one or more times each day, a substantial number (47.9%) read out loud only three times or less each

week. It appears that, although many children with DS are exposed to a large number of literacy events at home, a smaller but substantial number are not.

*Reader support.* Respondents were also asked to indicate the type of reader support they provided when reading out loud with their children with DS. A majority indicated that they read the text and pointed to and/or labelled pictures, and approximately 45% reported that they asked their child to point to or label pictures (Table 21). In contrast, much smaller percentages of respondents (20% to 30%) reported that they asked their child to tell a story in their own words or asked questions about what happened in the story, what would happen next, and/or why something happened. That these higher-order reading interactions appeared to receive less attention from parents raises questions about whether (a) the parent-child interactions that occur during storybook reading with persons with DS is optimal and (b) some parents might benefit from knowing more about how these types of questions may enhance potential reading ability (Marvin & Wright, 1997).

Unfortunately, widely available, parent-friendly materials such as those produced by educators such as Oelwein (1995) and Buckley (1995) encourage parents to read to their children with DS but do not provide specific strategies for engaging the child during story reading activities in ways that promote reading acquisition or fluency. The importance of this was emphasized in a pilot observational study by Hainsworth (1998) that examined how her interactions during storybook reading with her daughter with DS compared to the interactions of another mother reading to her two typical children. Hainsworth observed several notable differences in her storybook reading interactions, compared to the other mother. She asked fewer questions, made fewer references to previous experiences, used less repetitive questioning, and paused for shorter periods of time after questions. In response, her

daughter with DS made fewer vocal and nonvocal responses relative to the other two children. This and other research suggests teaching parents strategies for effective storybook reading with their children with DS might be a fruitful avenue for future research (Koppenhaver, Erickson, & Harris, 2001; Marvin & Wright, 1997).

*Library use.* In order to gauge the scope of community-based literacy activity, respondents were asked to indicate whether and in what manner they used the public library with their children with DS. The majority (65.5%) reported using the library to borrow books as the primary activity. Activities reported by approximately 25% of respondents included reading while at the library, borrowing CDs/audiotapes, and using computers; an additional nine activities were reported by approximately 15% of respondents. While the frequent use of the library is an encouraging finding, respondents' scope of use is somewhat disappointing. In addition, the fact that nearly 30% of respondents reported that their child with DS did not use the library at all is a concern that may be related to the limited development of literacy in those individuals.

Overall, the survey results appear to indicate that many parents of children with DS are optimistic about the potential for their children to learn to read and that they provide many opportunities for them to be exposed to others using a broad range of literacy materials in the home and in the community. These generally positive circumstances are counter-balanced by the narrow range of reading materials that are actually used at home by many individuals with DS, the limited types of parent-child interactions that appear to occur while reading, and the limited use of the library.

*Writing Abilities and Experiences of Individuals with Down Syndrome*

Survey items were included to determine (a) respondents' estimates of the current writing abilities of their children with DS; (b) writing materials typically used at home by others and by persons with DS; and (c) the frequency, duration, and types of support provided during home writing activities by persons with DS. As might be expected, respondents' estimates of their children's writing abilities varied according to chronological age. As was the case for reading, estimates of writing ability appeared to follow the pattern of writing development observed in typically developing writers.

*Estimated Writing Abilities*

Fewer than 25% of respondents for the 5:1 to 9:0 group identified any given ability from a list of writing abilities, with the exception of the approximately 50% who indicated that their child wrote/copied their name or familiar words. For each of the three oldest age groups (> age 9:1), 2 or 3 writing abilities were identified by a majority of respondents. As might be expected, there appeared to be a shift in emphasis from academic writing abilities such as writing in workbooks and writing answers to questions to more functional activities such as making lists and using notes to relay messages as the children got older. In general, the number of respondents reporting any particular writing ability increased and the range of abilities broadened as a function of age. Similar to respondents' reports of reading ability, children with DS appeared to lag substantially behind typically developing writers, and involvement in writing activities by a substantial minority was quite limited. Across age groups, the data appeared to reflect generally favourable circumstances for individuals with DS learning to write for basic academic and practical purposes. Somewhat analogous to Chall's (1983) description of the limitations of functionally illiterate readers, the increased

emphasis on functional writing skills in adults with DS may suggest that many are able to write primarily familiar text that does not extend beyond their existing knowledge and vocabulary.

### *Writing Materials and Frequency of Use*

As was the case for reading, limited access and/or exposure to a wide variety of writing materials did not appear to be a factor that could account for individuals with DS failing to develop a broad range of writing abilities. Overall, respondents reported that their children with DS saw others in their home using a wide range of writing materials and that they also used a variety of these materials at home to engage in actual writing tasks that appeared suited to their chronological ages. However, less than one-half of respondents indicated that their child wrote one or more times per day, and the duration of writing activities was reported to be less than 15 minutes per day for approximately 50%. This suggests that, while there may be an adequate breadth of writing experiences in the homes of these individuals, the frequency with which they engage in writing activities may be a concern.

### *Writing Supports Provided*

Respondents were also asked to indicate how they supported their child during writing/drawing activities. The types of writing/drawing supports varied as a function of age. For the youngest age group, a majority of respondents encouraged their children to write (89.7%), commented on their writing/drawing (79.5%), provided hand-over-hand guidance (76.9%), and helped position their writing instruments (59%). More than 50% of respondents for the 5:1 to 9:0 age group provided these same supports, with the addition of providing models for writing/drawing (63.8%). A majority of respondents for the 9:1 to 13:0 age group

indicated that they encouraged their children to write (78.7%), commented on the writing/drawing (74.5%), wrote/drew a model (68.1% ), and spelled words for their children (63.8%). For the adolescent group (13:1 to 19:0), a majority encouraged the person to write (59.5%), commented on writing/drawing (56.8%), spelled words (62.2% ), and answered questions (51.4%). Interestingly, relatively little support was reported by respondents in the adult group, with 51.2% indicating that they spelled words and 56.1% that they answered questions.

### *Literacy Goals, Interests, and Priorities*

Previous studies of the home literacy experiences have found that parental goals and expectations regarding literacy development differ considerably between parents of children with disabilities and parents of typically developing children. For example, Marvin and Wright (1997) compared the top priority goals of parents of children with speech language impairments (SLI), children with other disabilities but no speech language impairments (NSLI), and children with no disabilities (ND). Parents with SLI children chose *communicating effectively* as a top priority goal significantly more often than parents in the other two groups, while parents in the NSLI group chose *developing self-help skills* significantly more often. In contrast, parents of children in the ND group chose *learning to write, making friends, and increasing world knowledge* significantly more often than parents in the other two groups. Light and Kelford Smith (1993) reported that parents of typical preschoolers prioritized *literacy activities* higher than parents of preschoolers with physical disabilities. Marvin (1994) examined the priorities of parents whose children had either single or multiple disabilities and found that less than half of respondents in both groups selected learning to read and write as top priority goals. Similarly, Marvin and Mirenda

(1993) compared the priority goals of parents of preschoolers with disabilities, “at risk” preschoolers, and typical preschoolers. They reported that the top three priority goals of parents of preschoolers with disabilities were *communicating effectively*, *learning self-help skills* and *making friends*. Across these studies, the common element is that, at least for young children with disabilities, *learning to read* and *learning to write* are both prioritized consistently lower by parents than *communicating effectively*, *learning self-help skills*, and *making friends*.

In the present study, a majority of respondents identified learning to read as one of the top three goals in the 5:1 to 9:0 (56.3%) and the 9:1 to 13:0 age groups (62.1%), while a smaller but notable number identified learning to write as a top three goal in the 5:1 to 9:0 (18.8%) and the 9:1 to 13:0 (24.3%) groups. In all other age groups, learning to read was rated as a top three priority goal by approximately 30% of respondents and learning to write was similarly rated by approximately 10% of respondents. This suggests that there was a relatively narrow range between 5 to 13 years of age when these respondents considered learning to read and write as high priority goals. This is consistent with results indicating that 55.8% of respondents believed that children with DS make the most progress in learning to read between the ages of 6 to 12 and that 48.0% believed this to be the optimum age for learning to write.

Interestingly, the relatively low priority respondents assigned learning to read and write contrasted greatly with their reports of interest in these activities by their children with DS. With the exception of the youngest age group (70.2%), approximately 90% or more of all respondents reported that their children with DS were either “somewhat” or “very” interested in learning to read. A similar but slightly less pronounced pattern was observed for



writing; with the exception of the two youngest age groups (48.7% and 70.7%, respectively), approximately 90% or more of all respondents reported that their children with DS were either somewhat or very interested in learning to write. Given that the children's interest in learning to read and write was reported to be high, it is somewhat disappointing that parent priorities in these two areas are not higher.

That the period during which literacy is considered a priority goal is relatively brief, and that respondents estimate that the most progress in learning to read and write occurs between 6 to 12 years of age raises two concerns. First, home literacy activities that encourage children with DS to read and write may not begin early enough in some families (i.e., before the age of 6). Second, efforts to teach children to read and write may not be sustained long enough (i.e., after the age of 12). This is a particular concern for adolescents and adults, given data suggesting that adolescence and early adulthood might actually be the *optimal* time for some individuals with DS to learn to read and write (Fowler, Doherty, & Boynton, 1995). Not only was respondents' priority for learning to read and write low for the two oldest age groups, but school priority for literacy was also reported to decline after grade 6 and fewer than 50% of respondents indicated that a high/moderate priority was given in grades 10-12.

#### *Resources, Barriers, Needs, and Progress*

Several survey items were designed to identify perceived barriers to literacy development in individuals with DS, to determine what interventions could address these barriers, and to identify what community literacy resources are utilized.

#### *Literacy Barriers and Needs*

Approximately 80% of respondents indicated that at least one barrier from a list of 15 applied to their situation. Seven of the 15 barriers listed on the survey were selected by 10% or more of respondents as significant (Table 30). A lack of literacy programs, low expectations in existing programs, and lack of information about programs were the three most frequently cited barriers and were identified by approximately 20% of respondents. All three of these barriers are related to some aspect of literacy programs, and together suggest that a substantial number of parents have serious concerns about both the availability and the effectiveness of such programs in their communities. Lack of interest in reading and writing by the person with DS, too many competing interests for the person with DS, and lack of time by family members appeared to form another cluster of barriers related to motivation, interest, and priority. A third frequently chosen type of barrier was a lack of knowledge about reading and writing by the respondent.

Presented with a list of potential interventions that might foster literacy, a total of 65.1% of respondents indicated that either parent training in reading (35.4%) or writing (29.7%) would be helpful, while 58.8% indicated that a literacy program available to their child with DS at least once per week would be helpful. A majority of respondents (54.1%) also felt that either a private or peer reading tutor would be a helpful. Of these interventions, it is likely that the provision of parent training holds the most promise in terms of feasibility and affordability. Thus, it seems important to examine briefly the current state of parent-friendly reading instructional materials aimed at individuals with DS.

*Reading instruction for people with DS.* In North America, the materials produced by Buckley (1995) and Oelwein (1995) on how to teach children and adults with DS to read are widely disseminated to parents, professionals, and teachers at conferences, in journals, and in

lay publications. However, some of the views represented in these materials are not consistent with much of the research on how to best teach reading and writing. At issue is whether children with DS syndrome learn in essentially the same way as typically developing readers or whether they learn to read in a fundamentally different way. Buckley (1995) takes the position that children with DS can learn to read "without having any understanding of letter-sound correspondences at all, providing someone is on hand to teach them every new word" and that "there is no limit to the size of vocabulary that can be established in this 'look and say' way" (p. 166). However, she acknowledges that most children with DS do learn some letter-sound correspondences and apply them to reading and spelling. She also suggests that adults should point out letter-sound correspondences in the words a child with DS can recognize, but that the primary emphasis should be on a sight word approach to reading instruction because of the relatively superior visual and poor auditory memory skills of most individuals with DS. This approach is consistent with the controversial view of Cossu et al. (1993). that children with DS learn to read in the absence of phonological awareness. Similarly, Oelwein (1995) emphasizes that, for many children with DS, the visual modality is the most effective for teaching reading. In her popular book, *Teaching reading to children with Down Syndrome: A guide for parents and teachers*, Oelwein acknowledges the potential value of learning letter-sound correspondences for some children with DS but suggests that this is of secondary importance. She recommends that, once a sight word vocabulary is established, parents and teachers can begin to teach consonant letter-sound relationships if a child has the ability and interest. What all three of these approaches to teaching reading have in common is that they strongly advocate using a

sight word approach to teach reading, with scant emphasis on building phonological awareness skills.

Given that Buckley's (1995) and Oelwein's (1995) views in particular receive widespread exposure despite their lack of congruence with a substantial body of reading research, it is important that parents and teachers are exposed to alternative explanations of the reading process as well. The argument that children with DS learn to read in the absence of phonological awareness has been convincingly challenged on both methodological (Bertleson, 1993; Byrne, 1993; Cupples & Iacono, 2002) and empirical grounds (Cupples & Iacono, 2002). At the crux of the debate is whether phonological ability plays a significant role in the development of literacy for children with DS. Fowler (1993b) argued that "Both the process and products of language learning in persons with Down syndrome appear to be normal in all respects" (p. 128). If Fowler is correct, many of the conclusions found in Smith, Simmons, and Kameenui's (1998) meta-analysis, which identified six areas of convergence in the study of phonological awareness in typical readers, might apply to children with DS as well. These include: (a) phonological awareness is the specific processing ability that accounts for most of the variance in reading ability for most children; (b) a reciprocal relationship exists between reading and phonological awareness; (c) phonological awareness is increasingly viewed as a complex construct that is multidimensional and consists of several related but independent abilities; (d) phonological awareness is necessary but not sufficient to develop reading ability; (e) phonological awareness can readily be assessed; and (f) phonological awareness can readily be taught to children.

At least two studies strongly suggest that phonological awareness (PA) is indeed an important factor in the reading ability of children with DS and that further research is

warranted. Fowler et al. (1995) examined the relationship between phonological awareness and reading ability in 33 young adults with DS. Six readers who were assessed at a grade 4 reading level or higher all scored  $>15$  on a phoneme deletion task, while four readers who scored  $>15$  were assessed at a grade 3 level or lower. In contrast, all 18 subjects who scored  $< 15$  on a phoneme deletion task were assessed at a grade 3 level or lower. Fowler et al. concluded that PA appears to be a necessary but not sufficient condition for children with DS to learn to read. Further support for this position can be found in the only intervention study to date that has compared the effectiveness of sight word instruction to an "analytical" approach to reading that incorporated phonological awareness training for children with DS. Cupples and Iacono (2002) found that the analytical approach was more effective, although their results are limited by a small sample size ( $n = 7$ ).

A finding that is consistent across the results of Buckley (1985), Fowler et al. (1993), and the present study is that relatively few children or adults with DS advance beyond the early stages of reading. Fowler et al. observed that these early stages can be achieved almost entirely through sight word reading, and proposed that a lack of decoding ability precludes advancing to higher reading levels as much for children with DS as for readers in any other group. With regard to parent education, this suggests that, although the approaches to teaching reading advocated by Buckley and Oelwein (1995) may work very well for very young, beginning readers with DS, they may be less suitable for more advanced readers. The general point to be made is that parent training materials for reading and writing should be evidence-based in order to provide the most effective guidance to parents and teachers.

*Resources*

Respondents were asked to indicate what community literacy resources they had contacted during the six month prior to completing the survey on behalf of their children with DS. Approximately one-third had not contacted any resources, while 54.7% had contacted either a school or public librarian. No other resources were selected by more than 10% of respondents. This relatively low utilization of community resources in the six months prior to survey completion appears inconsistent with the large number of respondents (18.5%) identifying lack of information about literacy programs as a barrier, and the large number (65.1%) who identified parent training in reading or writing as a potentially helpful intervention to foster literacy in individuals with DS. It is possible that many people are largely unaware of the available community literacy resources or that the services provided by these resources are not seen by families as relevant. In both cases, outreach by the relevant organizations could serve to remedy the situation

*Limitations*

The results of this survey research should be interpreted cautiously in light of several limitations regarding the nature of self-report data, the representativeness of the sample, and the homogeneity of socioeconomic status in the sample. These factors potentially limit the reliability and generalizability of the overall results. First, the data are based on self-reports and might not reflect the actual literacy reading and writing experiences of the focus individuals with DS. For respondents commenting on older children and adults, self-report data are further limited by the difficulty involved in recalling information about events and perceptions from the distant past. In addition, respondents' comments about their children's school experiences might be coloured by the rather significant systemic changes in the

provision of special education services that have occurred over the past 25 years. Second, the respondents were not a randomly selected sample of parents with children with DS. Rather, they included parents who attended the Canadian Down Syndrome Society's 15<sup>th</sup> annual conference, were members of the Down Syndrome Research Foundation (DSRF), and/or were registrants in the Canadian Population Registry for Individuals with DS. Also, the overwhelming number of respondents (> 95%) identified English as the primary language in their homes, suggesting that the ethnic and cultural diversity present in Canadian society was not present in the sample. As a result of these factors, the sample may not be representative of the broader population of parents of children with DS. Third, respondents' occupational status and educational levels were relatively homogenous, based on scores assigned using an adaptation of the Hollingshead Four Factor Index of Social Status (as described in Scheider, 1986). The survey sample was relatively highly educated, with the average respondent except for those commenting on the adult age group classified as having *some university*. Similarly, the average respondent except for those commenting on the adult age group was classified as a *skilled worker*. Respondents commenting on the adult group had a mean educational level of *college* and a mean occupational status of *skilled manual worker*.

Despite these limitations, this study is believed to be the first survey research to describe the home and community literacy experiences of individuals with DS. It provides a substantive foundation on which to base future research efforts that compare the literacy experience of people with DS to those of normally developing readers and of other disability groups.

these potential research questions apply across age groups, while others pertain to one or more subsets of the five age categories used in the study. Some of the many questions suggested by the results include the following:

*Research Questions Related to Preschoolers with DS*

- Are parents of preschool children with DS effective storybook readers? If not, what interventions would be effective at teaching story reading skills to parents?
- Do preschool children with DS benefit from reading activities that incorporate phonological training?

*Research Questions Related to Elementary Age Children with DS (5:1 to 13:0)*

- What are teachers' beliefs and attitudes regarding reading instruction for children with DS?
- What instructional approach(es) do teachers take when teaching reading to children with DS?

*Research Questions Related to Adolescents and Adults with DS*

- Does the priority given reading and writing in schools decrease after the elementary school years?
- What type(s) of reading interventions are effective with adolescents and adults with DS?
- Do older students benefit from reading instruction that incorporates PA training?
- What is the relationship between reading/writing ability and access to educational and employment opportunities?



*Research Questions Related to All Age Groups*

- What beliefs and attitudes do educators have regarding the ability of children with DS to learn to read and write?
- How can the variety of reading materials used by individuals with DS at home be increased?
- What type(s) of reading and writing instruction are most effective?
- What factors in the school environment foster or discourage literacy involvement?
- What factors in the home environment foster or discourage literacy involvement?
- What is the relationship between parental priority and literacy achievement?
- At what age do children with DS make the most progress in learning to read and write?
- What impact has inclusion had on literacy attainment by individuals with DS?

*Conclusions*

The results of this survey revealed a high level of interest in learning to read and write among families and their children with DS. There appeared to be moderate to high levels of engagement in literacy-related activities across age groups, and these activities appeared to reflect developmentally normal patterns of reading and writing development. Overall, the results provide a broad descriptive overview of home and community literacy experiences and suggest many potentially valuable avenues of future research.

These positive findings are somewhat offset by issues that are likely to limit optimal conditions for learning to read and write. For example, this study suggests that there is a relatively narrow window of opportunity (i.e., between the ages of 6 to 12) when parents and teachers place a relatively high priority on the goals of reading and writing. In addition,

although the number of children and adults with DS who reach the early stages of reading appeared to be quite high, the number reaching more advanced stages was quite low. This suggests that many children with DS would likely benefit from a more sustained, focused approach to literacy development that begins in the preschool years, lasts throughout their entire school careers, and provides for maintenance and continued development in adulthood. Such an approach would require that significantly more evidence-based programs be available in both printed form and in settings such as community colleges. Currently, many parents and teachers rely on information derived from early, ground-breaking efforts to teach children with DS to read and write, as exemplified in the work of Buckley (1995) and Oelwein (1995). However, these approaches need to be reconsidered and expanded in light of recent research suggesting that approaches that are focused on phonological awareness may be more effective in helping children and adults with DS advance beyond the early stages of reading (e.g., Cupples and Iacono, 2002; Fowler et al., 1993). The results of this study and others point to the need to establish a sound body of research to guide reading and writing instruction for children and adults with DS across the lifespan.

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## Appendix A

### Home and Community Literacy Experiences of Individuals with Down Syndrome Parent/Guardian Home Literacy Survey

Please complete this survey if you are the **parent or guardian** of a person with Down syndrome.

#### Identification Information

- 1 Where do you live? City \_\_\_\_\_ Province \_\_\_\_\_
- 2 Date of birth of the person with Down syndrome: **day** \_\_\_\_\_ **month** \_\_\_\_\_ **year** \_\_\_\_\_
- 3 Gender of the person: \_\_\_\_\_
- 4 Your relationship to the person: \_\_\_\_\_
- 5 If the person attends school, indicate what grade: \_\_\_\_\_ not applicable: \_\_\_\_\_
- 6 If the person is an adult, **check all that apply**:
  - \_\_\_\_\_ attends a community college program
  - \_\_\_\_\_ attends a literacy program
  - \_\_\_\_\_ attends a vocational program
  - \_\_\_\_\_ employed part-time
  - \_\_\_\_\_ employed full-time
  - \_\_\_\_\_ does not work or attend a program
  - \_\_\_\_\_ other \_\_\_\_\_
- 7 What are **the two main ways** the person communicates at home?
  - \_\_\_\_\_ speech
  - \_\_\_\_\_ gestures
  - \_\_\_\_\_ manual sign language
  - \_\_\_\_\_ communication board with photographs or line drawings
  - \_\_\_\_\_ electronic communication device (indicate type: \_\_\_\_\_)
  - \_\_\_\_\_ other \_\_\_\_\_
- 8 What is the primary language spoken in your home? \_\_\_\_\_
- 9 What is your occupation? \_\_\_\_\_
- 10 What is your spouse's occupation? \_\_\_\_\_
- 11 What is your highest level of education? \_\_\_\_\_
- 12 What is your spouse's highest level of education? \_\_\_\_\_

**Literacy Abilities, Goals, and Resources**

13 **Check the one** statement that best describes the person's current reading ability.

- ☐ does not read
- ☐ recognizes letters of the alphabet
- ☐ recognizes 25-50 sight words
- ☐ reads simple texts (e.g. children's books)
- ☐ reads at a grade 1-2 level
- ☐ reads at a grade 3-4 level
- ☐ reads at a grade 5-6 level
- ☐ reads at a grade 7-8 level
- ☐ reads at a grade 9-10 level
- ☐ reads at a grade 11-12 level

14 **Check all** statements that describe the person's current writing ability.

- ☐ does not write
- ☐ writes some or all letters of the alphabet
- ☐ writes or copies name and other familiar words
- ☐ writes in workbooks or other beginning writing books
- ☐ writes simple stories or answers to questions
- ☐ writes email
- ☐ writes in a journal
- ☐ writes in a time organizer
- ☐ writes notes to relay messages
- ☐ writes lists
- ☐ writes letters
- ☐ completes forms
- ☐ writes postcards
- ☐ writes school assignments

15 Please indicate the three most important goals that you have for the person at this time. **Number from 1 (most important) to 3 (least important of the three):**

- ☐ learning self-help skills
- ☐ communicating effectively
- ☐ learning to read
- ☐ learning to write
- ☐ making friends
- ☐ developing recreational interests and skills
- ☐ developing vocational skills
- ☐ developing knowledge about the world
- ☐ other \_\_\_\_\_

16 How interested is the person in reading? **(Check one only):**

- ☐ not at all
- ☐ somewhat
- ☐ very interested

17 How interested is the person in writing? **(Check one only):**

- ☐ not at all  
☐ somewhat  
☐ very interested

18 How interested is the person in drawing? **(Check one only):**

- ☐ not at all  
☐ somewhat  
☐ very interested

19 Which of the following best describes the person's school experience?  
**(Check all that apply):**

**Grades K-3**

- ☐ regular class  
☐ resource room  
☐ special class

**Grades 4-6**

- ☐ regular class  
☐ resource room  
☐ special class

**Grades 7-9**

- ☐ regular class  
☐ resource room  
☐ special class

**Grades 10-12**

- ☐ regular class  
☐ resource room  
☐ special class

20 How much **priority** was given at school to reading and writing instruction?  
**(Select one only):**

**Grades K-3**

- ☐ high priority  
☐ moderate  
☐ low  
☐ very low

**Grades 4-6**

- ☐ high priority  
☐ moderate  
☐ low  
☐ very low

**Grades 7-9**

- ☐ high priority  
☐ moderate  
☐ low  
☐ very low

**Grades 10-12**

- ☐ high priority  
☐ moderate  
☐ low  
☐ very low

21 Which best describes the priority given reading and writing instruction to the person as an adult?  
**(Select one only):**

- ☐ does not apply  
☐ high priority  
☐ moderate priority  
☐ low priority  
☐ very low priority

22 Which of the following literacy resources have you used or contacted on behalf of the person at least once in the last 6 months? **(Check all that apply):**

- ☐ Literacy BC  
☐ school librarian  
☐ public librarian  
☐ library general collection  
☐ library adult basic education collection  
☐ continuing education programs (library, school, college)  
☐ private literacy tutor  
☐ peer literacy tutor  
☐ free literacy program  
☐ fee for service literacy program  
☐ have not contacted any literacy resources in the last 6 months  
☐ other \_\_\_\_\_

**Reading**

23 What printed material does the person see others in the home read? (Check all that apply):

- ☐ magazines
- ☐ adult books
- ☐ comic books
- ☐ picture books
- ☐ story books
- ☐ dictionary/encyclopedia
- ☐ newspapers
- ☐ catalogues/brochures/advertisements
- ☐ newsletters
- ☐ letters/postcards
- ☐ email/internet
- ☐ bills
- ☐ schedules
- ☐ recipes
- ☐ cheque books/budget books/calendar organizers
- ☐ notes
- ☐ adult basic education reading material
- ☐ closed captions on TV
- ☐ computer s (software programs, games, stories, etc.)
- ☐ does not see others in the home read
- ☐ other \_\_\_\_\_

24 What printed material does the person read in the home? (Check all that apply):

- ☐ magazines
- ☐ adult books
- ☐ comic books
- ☐ picture books
- ☐ story books
- ☐ dictionary/encyclopedia
- ☐ newspapers
- ☐ catalogues/brochures/advertisements
- ☐ newsletters
- ☐ letters/postcards
- ☐ email/internet
- ☐ bills
- ☐ schedules
- ☐ recipes
- ☐ cheque books/budget books/calendar organizers
- ☐ notes
- ☐ adult basic education reading material
- ☐ closed captions on TV
- ☐ computer s (software programs, games, stories, etc.)
- ☐ does not read in the home
- ☐ other \_\_\_\_\_

25 How often does the person use any of the printed materials listed in question 24? **(Check one):**

- ☐ 0-1 times per week
- ☐ 2-3 times per week
- ☐ 4-5 times per week
- ☐ once per day
- ☐ many times per day

26 How frequently do you or someone else read aloud to the person? **(Check one):**

- ☐ 0-1 times per week
- ☐ 2-3 times per week
- ☐ 4-5 times per week
- ☐ once per day
- ☐ many times per day

27 When someone reads aloud to the person at home, how much time is typically spent afterwards talking about what was read? **(Check one):**

- ☐ not applicable
- ☐ less than 15 minutes
- ☐ 15-30 minutes
- ☐ 30-60 minutes
- ☐ more than 60 minutes

28 When someone reads a book with the person, what does the person reading usually do? **(Check all that apply):**

- ☐ person is not read to at home
- ☐ tells the story in his/her own words
- ☐ reads the text in the book
- ☐ points to the pictures and labels them
- ☐ points to the words in the book
- ☐ asks the person to label the pictures (e.g. What's this?)
- ☐ asks the person to point to the pictures (e.g. Show me the \_\_\_\_\_.)
- ☐ asks the person what happened in the story
- ☐ asks the person what will happen next
- ☐ asks the person why something happened
- ☐ other \_\_\_\_\_

29 How frequently does the person read by himself or herself at home? **(Check one):**

- ☐ 0-1 times per week
- ☐ 2-3 times per week
- ☐ 4-5 times per week
- ☐ once per day
- ☐ many times per day

30 When the person reads by himself or herself at home, how much time is usually spent reading?  
(Check one):

- ☐ not applicable
- ☐ less than 15 minutes
- ☐ 15-30 minutes
- ☐ 30-60 minutes
- ☐ more than 60 minutes

31 About how many books does the person own? \_\_\_\_\_

32 Indicate how the person uses the library (Check all that apply):

- ☐ does not go to the library
- ☐ initiates going to the library
- ☐ goes to the library with family member
- ☐ goes to the library independently
- ☐ borrows CDs/audio books
- ☐ occasionally borrows books
- ☐ regularly borrows books
- ☐ borrows magazines
- ☐ asks for help from the librarian
- ☐ uses computers in the library
- ☐ uses photograph collection
- ☐ attends storytelling sessions
- ☐ listens to speakers
- ☐ reads while at the library
- ☐ writes while at the library
- ☐ does school work with a friend at the library
- ☐ does school work independently at the library

### Writing

33 Which of the following writing/drawing materials does the person see you or others use in the home? (Check all that apply):

- ☐ person does not see writing/drawing materials used in the home
- ☐ pencil/pen and paper
- ☐ crayons, magic markers
- ☐ paintbrushes, paints
- ☐ chalk/chalkboard
- ☐ magnetic/felt letters
- ☐ computer
- ☐ typewriter
- ☐ calculator
- ☐ other \_\_\_\_\_

34 When someone draws or writes with the person, what does the helper usually do to help? (**Check all that apply**):

- ☐ no one draws or writes with the person
- ☐ imitates or copies the person's strokes/letters/pictures
- ☐ positions a writing utensil in the person's hand
- ☐ provides hand-over-hand assistance or guidance
- ☐ comments on what the person is drawing/writing
- ☐ sits silently and watches while the person draws/writes
- ☐ encourages the person to "draw/write more"
- ☐ tells the person what to draw/write or which colours to use
- ☐ spells words aloud for the person
- ☐ draws/writes a model for the person to copy
- ☐ directs the person to look around the room for a model to copy
- ☐ answers the person's questions
- ☐ other \_\_\_\_\_

35 How does the person participate in writing activities at home or in the community? (**Check all that apply**):

- ☐ does not participate in writing activities at home
- ☐ plays with or writes with magnetic letters
- ☐ chooses a writing or drawing activity
- ☐ draws pictures with pencil, felt marker, paintbrush etc.
- ☐ draws pictures using a computer
- ☐ completes spelling or grammar worksheets
- ☐ writes text independently using pencil, pen, or typewriter
- ☐ writes text independently using computer
- ☐ writes text independently using an electronic communication device with printer
- ☐ practices writing or typing letters of the alphabet
- ☐ tells stories for others to write down
- ☐ plays with writing and drawing toys (Etch-a-sketch, etc.)
- ☐ copies letters or words
- ☐ uses or plays with a calculator
- ☐ other \_\_\_\_\_

36 How often does the person do some kind of writing, drawing, or "pretend writing" at home? (**Check one**):

- ☐ 0-1 times per week
- ☐ 2-3 times per week
- ☐ 4-5 times per week
- ☐ once per day
- ☐ many times per day

37 When the person writes, how much time does he/she usually spend in the activity? (**Check one**):

- ☐ not applicable
- ☐ less than 15 minutes
- ☐ 15-30 minutes
- ☐ 30-60 minutes
- ☐ more than 60 minutes

### Progress and Needs

38 How much progress have you seen in the person's reading, writing, and drawing this year?

#### Reading

- ☐ no progress
- ☐ a little progress
- ☐ moderate progress
- ☐ a lot of progress

#### Writing

- ☐ no progress
- ☐ a little progress
- ☐ moderate progress
- ☐ a lot of progress

#### Drawing

- ☐ no progress
- ☐ a little progress
- ☐ moderate progress
- ☐ a lot of progress

39 **Check all** of the following statements that best describe the highest level at which you believe the person will ever be able to read and write?

- ☐ will not be able to read or write
- ☐ will be able to recognize the letters of the alphabet
- ☐ will be able to recognize fewer than 25 sight words
- ☐ will be able to read and spell 25-50 words
- ☐ will be able to read simple texts and do basic writing
- ☐ will be able to read newspapers and magazines
- ☐ will be able to write letters and stories
- ☐ will be able to read novels for pleasure
- ☐ will be able to compete in a college or university classroom



40 Which of the following are significant barriers to literacy development for the person? (**Check all that apply**):

- ☐ person is not interested in reading or writing
- ☐ person has too many other interests
- ☐ family member does not have time to join in reading and writing activities
- ☐ lack of books
- ☐ lack of literacy programs
- ☐ transportation issues prevent attending literacy programs
- ☐ lack of information about reading and writing programs
- ☐ lack of knowledge about reading and writing development
- ☐ literacy programs are too expensive
- ☐ reading and writing materials are too expensive
- ☐ literacy program length is too short
- ☐ time between classes in literacy program is too long
- ☐ expectations in the school or literacy program are too high
- ☐ expectations in the school or literacy program are too low
- ☐ literacy program content is either too easy or too difficult
- ☐ none of the above
- ☐ other \_\_\_\_\_

41 Which of the following would be most helpful in improving the person's reading and writing ability? (**Check only three**):

- ☐ program with class 1-2 times per week
- ☐ program with class 3 or more times per week
- ☐ parent training in teaching reading
- ☐ parent training in teaching writing
- ☐ peer tutor
- ☐ private tutor
- ☐ suggestions from the person's current teacher on how to encourage reading and writing
- ☐ none of the above
- ☐ other \_\_\_\_\_

42 At what age do you think people with Down syndrome make the most progress in their reading and writing ability? (**Check all that apply**):

**Reading**

- ☐ 0-5 years
- ☐ 6-12
- ☐ 13-19
- ☐ 20-25
- ☐ 26 and older
- ☐ don't know

**Writing**

- ☐ 0-5 years
- ☐ 6-12
- ☐ 13-19
- ☐ 20-25
- ☐ 26 and older
- ☐ don't know

43 Do you have any additional comments?

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## Appendix B

### Questionnaire Feedback Form

Please complete this form after completing the questionnaire.

1 Was the questionnaire too long?

☐ yes

☐ no

2 How long did it take you to complete the questionnaire? \_\_\_\_\_

3 Was the questionnaire well organized?

☐ yes

☐ no

4 Were the questions clear?

☐ yes

☐ no

5 If you answered no, indicate which questions were not clear. \_\_\_\_\_

6 Were any of the questions too difficult?

☐ yes

☐ no

7 If you answered yes, indicate which questions were too difficult. \_\_\_\_\_

8 Did any of the questions make you uncomfortable?

☐ yes

☐ no

9 If you answered yes, indicate which questions made you uncomfortable. \_\_\_\_\_

10 Do you think the survey allowed you to provide an accurate account of the literacy history and abilities of the person with Down syndrome?

☐ yes

☐ no

Comments: \_\_\_\_\_

11 Are there any questions you feel should have been included?

\_\_\_\_\_

12 Do you have any other suggestions for improving the questionnaire? (e.g. font size, spacing, etc.) \_\_\_\_\_

Appendix C

**Letter of Support from Down Syndrome Research Foundation**

April 20, 2004

Dear Parent or Guardian,

The Down Syndrome Research Foundation is very pleased to participate in a research project entitled "Home and Community Literacy Experiences of Individuals With Down Syndrome."

The project is being conducted by Dr. Pat Mirenda and Mr. Brian Trenholm of the University of British Columbia. The purpose of the project is to gather much-needed information about the experiences of people with Down syndrome at home with respect to reading and writing instruction.

I believe this study will gather valuable information about the role of literacy in the lives of these individuals, and I encourage you to read the enclosed materials carefully and return the survey by the due date. Dr. Mirenda and Mr. Trenholm will provide a summary of the results to the DSRF and we will be happy to share this information with families who participate.

Yours sincerely,

Josephine Mills,  
Executive Director,  
Down Syndrome Research Foundation

## **GIFT CERTIFICATE AND BOOK ENTRY FORM**

To enter the lottery for a \$50.00 gift certificate and book, please complete this form, place it in the small envelope, seal it, and return it with the completed questionnaire in the enclosed large, stamped self-addressed envelope. Except for the winning form, all forms will be destroyed without being opened after the lottery.

**Name:** \_\_\_\_\_

**Address:** \_\_\_\_\_

\_\_\_\_\_  
**Phone number or email:** \_\_\_\_\_