Raising a child with Down syndrome: parents' evaluations of health information and support

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This study surveyed over 200 caregivers of persons with Down syndrome about availability of health information and resources. Only a third had excellent resources with clear and consistent information to support the development of their child. Half knew about the Preventive Medicine Guidelines; 36% reported health concerns in their children. Most felt they were required to seek information on their own. Pediatricians, Infant Development Program workers and family physicians were all found to be important and helpful to parents. There was a clear need expressed for professionals and public to be better informed regarding Down syndrome and for improved access to information for themselves.

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Introduction

Families are usually unprepared for the birth of a child with Down syndrome and for the impact it will have on their lives. Prenatal diagnosis has been available since the 1970s but the mean world-wide incidence rate has stayed about the same (Wishart, 1993). The risk of miscarriage associated with procedures such as amniocentesis outweighs the risk of Down syndrome for most women, so it is offered routinely only to women over 35, or those with a previous Down syndrome pregnancy. Improved social and educational opportunities for children with Down syndrome may cause some families to consider it not a sufficient reason to terminate a pregnancy (Wishart, 1991).

In addition, survival of persons with Down syndrome has steadily improved. In the 1950s about half survived their first year (Carter, 1958). Now, over 60% are expected to reach age 50, and 14% can be expected to survive to age 68 (Baird and Sadnovick, 1989). There are also more women in the 35-49 age bracket and a trend toward late child bearing. As a result of all these factors, Down syndrome is increasing to levels higher than seen in the past 20 years (Baird and Sadnovick, 1989; Nicholson and Alberman, 1992; Goodwin and Heuther, 1987).

Children and adults with Down syndrome have a significant impact on our "special services" with their needs for support, medical intervention, educational resources, social and recreational opportunities. The need to make decisions about such things as well as the trend toward family centered care from health care providers require that families have as much information as possible to support the growth of their family member with Down syndrome.

The present survey was conducted to ask those directly affected by Down syndrome to describe what information or services would assist them in raising a child with Down syndrome and if there was a need for a Down Syndrome Health Resource in the Province of British Columbia (BC), Canada. They were also asked if they were aware of the proposed health care guidelines recently adopted by the Canadian Paediatric Association. These are similar to the American Preventive Medicine Checklist and indicate the type of health assessment and frequency recommended throughout the lifespan for persons with Down syndrome (Coleman and Lentz, 1989). The goal was to determine how widespread was the use of these guidelines, and if there was a need to encourage greater use; also, if there were large numbers of health concerns that were not being addressed.

With such information it might be possible to recommend changes, fine-tune existing services or design new ones. This paper reports the results of the survey of parents and caregivers of persons with Down syndrome about their perceptions of the availability of information, resources and health care.

Method

A questionnaire, cover letter and self-addressed stamped envelope were mailed to families who have a member with Down syndrome. Mail survey has been demonstrated to be as efficient a means of data collection as telephone interviews and far less costly (Wishart, Macleod and Rowan, 1993). Included were members of the Lower Mainland Down

Syndrome Society (LMDSS), BC members of the Canadian Down Syndrome Society (CDSS), and families seen at Sunny Hill Health Centre for Children. The Infant Development Program (IDP), Child Development Centres (CDCs) and organizations providing services for adults were also contacted and asked to pass the questionnaire to any families they knew. Five hundred questionnaires were mailed out. Over 200 responses were received within four months.

Attempts were made to reach as many families as possible but it is not known exactly how many received the questionnaire and what proportion of possible families were represented by the replies. Families with the most concerns would be the most likely to voice their opinions; those who were satisfied may have been under represented.

There were three parts to the questionnaire: 1) a request for background information including sex and age of the person with Down syndrome, location in BC and the respondent's relationship to the person; 2) eight questions; 3) a request for comments or suggestions about what they would like to see in a Down Syndrome Health Resource. Most but not all respondents answered most questions, hence the number in each tally varies.

Results

The Sample.

Ninety-four percent (196) of the 209 responses were from parents; 83% mothers. The remainder were other relatives or caregivers. Eighty-seven percent of their offspring were natural; 10% adopted and two families had one natural and one adopted. There were slightly more boys (54%) than girls.

The majority of persons with Down syndrome in BC are young people since health and life expectancy have improved in the last 25 years. This was reflected in the responses to the survey. Almost half (46%) had children five or under; 38% 6-12 yrs.; 12% teenagers, and almost 4% 20 years or older.

The regional distribution matched the population distribution in BC with all regions represented proportionally. Seventy-three percent of the parents and 80% of the other caregivers belonged to an organization that provides information about Down syndrome.

The Questions.

The parents were asked to rate from one to seven, who was the most to least important or helpful to them. They were provided with a list of examples, such as pediatrician or Infant Development Program (IDP) worker and a category for "other". The responses for each source of help or information were tabulated separately. They were weighted (1-7) and multiplied by the number of persons giving the same weight. These were summed and divided by the total number of responses to give a mean score, from 1 (best) to 7 (worst) for each source. The scores were rank ordered and the percentage of parents rating each noted. A low percentage reflects either that the family had no contact with that individual about a particular question, or that they weren't helpful or important.

Question 1: **"Who provides you with health care information about Down syndrome?"** The responses are in Table 1 on the left. Eighty-one percent responded to the category, "Self, through searching libraries, associations, etc." Of these, 70% reported it was the most important with ratings of 1 or 2. The family doctor was a moderately important source of information, but ranked behind the IDP, pediatrician or physiotherapist. Since half of these families had very young children, it is likely that they had more contact with IDP or a physiotherapist and only saw their doctor or pediatrician when there was a health concern.

Question 2: **"When you seek help with your problems about health care, who helps you and how helpful are they?"** Similar to Question 1, most families reported themselves to be the most important in obtaining help with health care (Table 1). Of the 80% who indicated their family doctor, only 46% found her/him to be "very helpful". The pediatrician and IDP were rated at a higher level with almost 60% of the 54-63% who responded giving a rating of 1 or 2, "very helpful". It appears more people report seeing their family doctor about health care, but are more often satisfied with the pediatrician or IDP. Fewer than 40% of the families rated other professionals or family members and did not find them very helpful in solving health problems.

Table 1. Rank order of responses to questions, "Who Provides Health Information?" and "Who Helps with Health Problems?" by families of persons with Down syndrome

	Health Info. rank, (score), % responding	**% rating 1 or 2 , "most important"**	**Health Help rank, (score), % responding**	**% rating 1 or 2, "most important"**
Self	1 (2.1), 81%	70%	1 (2.1), 67%	70%
IDP	2 (2.6), 67%	63%	3 (2.8), 54%	60%
Pediatrician	3 (3.3), 67%	43%	2 (2.5), 63%	59%
Physio/OT	4 (3.6), 56%	34%	5/6 (3.2/3.5)	44/37%
Family Doctor	5 (4.2), 75%	26%	4 (2.9), 80%	46%
CHN	6 (4.7), 48%	22%	7 (4.1), 35%	31%
Family Member	7 (5.4), 49%	12%	8 (4.6), 37%	21%
Social Worker	8 (5.6), 46%	9%	10 (4.8), 34%	13%
Teacher	---	—	9 (4.7), 34%	19%

Question 3: **"How clear and consistent has been the health care information about your child?"** Ninety-seven percent responded to this question, with a mean rating of 3.4 meaning "fairly clear and consistent. "Thirty-five percent rated their health information as "very clear and consistent" with only 13% who found it "conflicting/confusing".

Question 4: **"What are your sources of information on Down syndrome for such things as child development, education, family support or recreation?"** Parents again ranked themselves as the most important resource. The IDP, other parents and advocate organizations were also rated highly (mean 2.3-2.6; Table 2). The family doctor and pediatrician were mentioned by just over half of respondents, but considered only moderately helpful in these areas, (mean scores 4.9 and 4.0). Perhaps surprisingly, teachers, social workers, community health nurses or recreation persons were not mentioned by very many families (35-45%) or considered very important in giving non-health information. Two-thirds of the families had children over three and would be expected to be in a preschool or school setting and have a teacher and/or social worker.

Table 2 Rank order of responses to "What are your sources of information for such things as child development, education, family support or recreation?" by families of children with Down syndrome.

Service	**Rank order, (score), % responding**	**% rating 1 or 2. "most important"**
Yourself	1 (2.0), 79%	76%
IDP	2 (2.3), 58%	71%
Other parents/ advocate organizations	3 (2.6), 63%	57%
Physiotherapist	4 (3.8), 43%	34%
Pediatrician	5 (4.0), 54%	26%
Teacher	6 (4.3), 45%	27%
Social Worker	7 (4.4), 45%	23%
Family Members	8 (4.5), 41%	25%
Occupational Therapist	9 (4.6), 33%	19%
Family Physician	10 (4.9), 57%	18%
Community Health Nurse	11 (4.9), 37%	16%
Community Recreation Staff	12 (5.0), 35%	10%

Question 5: "**Do you get the information needed by your family to support the development of your child?**" Ninety-four percent of the families responded to this question and gave it a mean rating of 3.7, exactly half-way between "excellent resources/no need" and "no resources/ high need." Thirty percent reported very positively, and 18% very negatively.

Question 6: **"Would it be a good idea to set up a Provincial Down Syndrome Health Resource to coordinate resources and provide medical, child development and educational information for families?**" The response to this was overwhelmingly, "Yes, very much needed," with a mean score of 1.6 from the 97% of parents who responded. Eighty-eight percent gave it a rating of 1 or 2, while only 4% felt it was "not needed", rating it 6 or 7. Table 3 gives the rank order of services they would like to see in such a resource.

Table 3 Rank order of services parents would like to see in a Down Syndrome Health Resource

Service	**Rank Order and Rating on scale of 1-7**	**Percent rating 1 or 2 "very much needed"**
Medical and new treatment information	1,1.5	89%
Assessment facility for evaluation of problems related to:		
Preventive health	2,1.7	84%
Social/emotional	3, 1.7	83%
Learning/behavior	4, 1.7	83%
Medical	5, 1.7	83%
Surgical	6, 1.8	79%
Person to provice referral to local resources	7, 1.8	77%
Information for local resources	8, 1.9	76%
Lending library	9, 2.0	71%
Information on advocate organizations	10, 2.2	71%
Transition planning to adult services	11, 2.2	68%
Contact with other parents	12, 2.5	57%

All of the possible services were rated as highly needed but parents were most interested in access to the latest medical information and a facility for evaluating individual children for learning and behavior as well as medical and surgical concerns. Lower on the list were a library, information on advocate organizations or meeting other parents. These may be less in demand because such services do exist, although not evenly distributed throughout the province. The relatively lower rating of need for transitional planning to adult health and social services may reflect the young age of the sample and the fact that these parents are not yet concerned with adult issues.

When asked for their own suggestions as to what they would like to see in a Down Syndrome Health Resource, the parents echoed the items in Table 3. A minority rightly pointed out that there are already services in place and they would not like to see a centralized facility that required travelling for families.

The greatest need appears to be for hospitals, doctors, dentists, other professionals and even the public to have more information about Down syndrome. For themselves, they would like access to people who do know something about Down syndrome, possibly via a toll-free telephone line. They would also like workshops and parent networking. Common to all parents of children with developmental disabilities, they would like to learn more strategies for teaching their children, changing their behavior and generally enhancing their growth. Job training and work opportunities for young adults were on the agenda for some.

Question 7: “**Do you know of the proposed guidelines about when to give medical exams and lab tests to children with Down syndrome?**” Only 50% (94 of 189) reported that they knew about these. Fifty two of the positive respondents (55%) saw it as their family doctor’s responsibility to insure that the examinations were done. Thirty-six percent felt their pediatrician should be responsible, and 21% saw it as the job of an “other specialist”.

Finally, to get a general picture of the health concerns in this sample of persons with Down syndrome, the caregivers were asked Question 8: “**Do you currently have health concerns about your child which you feel are not being adequately addressed**?” Ninety-seven percent of the parents answered this question, with 36% (68) indicating concerns. Note that this is not the actual incidence of health problems in children with Down syndrome, but the number reported as being a current worry to parents in this group of 196, half of whom had children under five years.

Table 4 gives the type and incidence figures of health concerns to be expected in Down syndrome compared with the incidence reported by the BC parents (Rogers and Roizen, 1991; Pueschel, 1992). Most (67%) of the concerns were the common ones, but several were unique. For example, there was one each who reported concern about juvenile rheumatoid arthritis, skin problems, fatigue, transient neonatal leukemoid reaction, night waking, diabetes, and autism in their family member with Down syndrome. Ten percent of the families considered a need for speech therapy a health concern.

Table 4 Health concerns commonly seen in persons with Down syndrome and incidence reported by this sample of 209 caregivers

Health Concern	Incidence in general Down syndrome population	Number and incidence of current concern in B.C. parents
Congenital heart disease	40-60%	0
Congenital abnormalities of gastrointestinal tract	12%	1 (<.05%)
Ophthalmological problems	30-70%	1 (<.05%)
Thyroid dysfunction	15-20%	2 (1%)
Orthopedic/skeletal problems	15%	4 (2%)
Audiological deficits	80%	4 (2%)
Dental problems	80-100%	1 (<.05%)
Nutrition/weight	50% or more	14 (7%)
Behavior disorders	up to 22%	3 (1.5%)
Seizures	8%	3 (1.5%)
Upper respiratory infections	more common in DS	5 (2.5%)

Discussion

This paper reports the results of a survey of over 200 parents or caregivers of persons with Down syndrome about their perception of health information and support in the Province of BC, Canada. The survey aimed to identify any unmet needs.

On the whole parents reported that they got the information they needed, but only 30% felt they had excellent resources to support the development of their child and almost 20% reported “no services/high need”. Only a third felt the health information was “clear and consistent” and more troubling was the report that they, the parents, were the most important resource in finding health care information. The parents, IDP and pediatrician were the only sources considered “very important” by more than 40% of families. The respondents, 73% of whom belonged to an organization and who rated themselves as the main source of information for both health and non-health questions, indicated a very high desire for better informed professionals, more information about their individual children and resources for themselves. While it is admirable that this is such a resourceful group of parents, it suggested that the health and allied professionals have not done an adequate job, especially with the up to 40% of families with various needs.

Only 63% reported using a pediatrician but they were slightly more satisfied than the 80% who saw a family physician for their health concerns. (Families apparently use both). Pediatricians probably had exposure to developmental disabilities in their training and thus had more up-to-date information about Down syndrome. Whereas the perceived lack of information and support given by family physicians may be seen as a serious lack in health care, particularly by parents, it must be recognized that Down syndrome is a relatively rare medical condition. One study in the UK reported only 60% of general practices had persons with Down syndrome on their lists, and the average GP would be likely to have a patient with Down syndrome only once every 37 years (Murdoch, 1982).

The Health Care Guidelines were familiar to just half of the parents surveyed, and most saw it as their family physician’s or pediatrician’s job to carry them out. It is interesting that there were not more parents aware of the Guidelines since 85% reported that they belonged to an organization concerned with Down syndrome, and most reported they were the ones who sought health information for their families.

Just over a third reported what they saw as inadequately addressed health concerns but none of these were the severe ones commonly seen in Down syndrome. It would appear that major health problems, such as congenital heart disease or gastrointestinal malformation, are being identified and treated. The low rate of all the health problems commonly found in Down syndrome may reflect adequate attention being given to them by health care professionals. What parents indicated here as not being adequately addressed were what are often chronic problems, such as weight gain, seizures, or “constantly draining ear.” These may not be life threatening although they could be “quality-of-life” threatening. It may be that the incidence of health concerns in this sample is low due to the age of the sample, half under five years. Parents of very young children may yet have to worry about eye, ear, weight or behavior problems.

Only one parent mentioned concern about dental problems, yet reports indicate that almost all persons with Down syndrome will experience malocclusions or periodontal disease (Rogers and Roizen, 1991). Either dental care is very good for these families or the young people have not yet developed the problems.

Because of improved health care and increased opportunities for persons with Down syndrome, they will live longer and will be much more a part of the community than in the past. The expectation for improved health care will certainly be part of these families goals for their children as they move into adolescence and adulthood. The Preventive Health Guidelines for Persons with Down Syndrome are a helpful reminder to parents and physicians alike of the possible problems and areas to monitor and of the need to be vigilant and proactive about health care for this population with their unique needs.

In recent years there have been major changes in attitudes towards persons with Down syndrome. Infants and children are no longer institutionalized and separated from their families and community. They have the benefits of loving, stimulating homes; health problems are addressed locally and they are living longer; they receive early intervention, attend neighborhood schools and have opportunities for independent living and employment. Parents have advocated for increased service and support and have succeeded. The result is a generation of young people with Down syndrome who are healthier, more competent and integrated into the community. Other members of the community have greater awareness and acceptance of them. Despite these positive trends, the voices of the parents cannot be ignored. Those who work with families are obligated to attempt better to meet their needs with improved information services and support.

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