

Multiple Birth Families: The Forgotten Constituents

MAPPING THE FUTURE PROJECT FOCUS GROUP FINDINGS

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BACKGROUND

“Sufficient unto the day is one baby. As long as you are in your right mind, don’t ever pray for twins. Twins amount to a permanent riot; and there ain’t any real difference between triplets and an insurrection.”

Mark Twain, the Babies Speech, 1879

This funny but revealing quote from Mark Twain makes us understand how challenging having multiples can be for the growing number of families with twins, triplets or more. Yet, as a consequence of medical advances in the fields of infertility and newborn care, there has been a dramatic rise in the number of multiple birth children born. Each year over 9,000 multiple-birth babies are born in Canada. Compared to single born babies, these infants are at higher risk of death and illness during the prenatal period and in the first few months as they are usually born earlier and smaller. In Canada, where multiple birth infants represent 1 in 40 births, multiples account for: 1 in 6 preterm births; 1 in 5 low birth-weight births; and 1 in 4 very low birth-weight births. As these children grow, they are more vulnerable to long-term health problems including developmental delays, behaviour problems, excessive dependency on each other, and rivalry. As well, their parents often experience physical, emotional and financial stress. This stress, in combination with the lack of access to special information and support, places multiple birth children and their siblings at an increased risk of child abuse and neglect.

These disproportionate health and psychosocial risks identify women who are expecting multiples as primary targets for efforts to reduce low birth weight and infant mortality, and to support family functioning. Although Canada has one of the best health care systems in the world, multiple births are often overlooked by health care, education, and social service providers. If the children are to develop and grow at the same rate as single born children, multiple birth families need access to health care, social services, and education which respect their differences from single born children.

Many multiple families have expressed through focus groups similar concerns and experiences as the women living in difficult situations quoted in the Best Start Book: *Reducing the Impact*. Included in their list of barriers and issues are “lack of food security, elevated stress levels, lack of rest, lack of transportation and other accessibility issues, social isolation and lack of support from family and social networks, lack of relevant information about available resources and services, community and structural barriers absence of family and community support ...”

STATEMENT OF PURPOSE

Multiple Births Canada has prepared this report for three main reasons:

- ♦ To alert Canadians to the challenges faced by multiple-birth families;
- ♦ To raise awareness, among the public, service providers and decision-makers, of the met and unmet needs of multiple-birth children and their families; and
- ♦ To stimulate the development of preventative health and parenting education and psychosocial services to reduce the risks associated with multiple birth.

FOCUS GROUPS

In order to more fully understand the services needed by multiple-birth families, Multiple Births Canada (MBC) partnered with the Canadian Institute of Child Health (CICH) to carry out a series of focus groups with parents of multiple birth children ranging in age from birth to five years. Fifty-one mothers and fathers of twins, triplets and quadruplets participated in seven focus group sessions, in four Ontario regions (north, south, east and west) between September and December 2001. A variety of parenting perspectives were elicited such as special needs children, single parents, teen parents, francophone families, immigrant families, and bereaved parents. Financial support for this research was provided by the Ontario Trillium Foundation.

This report summarizes the findings of these structured focus group sessions.

WHAT WE HEARD

The focus groups served to illuminate many important factors related to the challenges of multiple birth children and their families. Five main themes emerged from the parent need focus group information:

1. Reality of families with multiples

Participants identified numerous burdens associated with parenting multiples:

- Physical strains – Respite is needed during the prenatal and postnatal periods.

“Right now, I feel I am just surviving.”

- Financial strains – Many multiple birth families are struggling with poverty. Some studies show that 14.4% of Canadian children live in poverty. Although parents of multiples assume extraordinary financial commitments, they often need to manage the household on only one salary. For example, high priced multiple birth equipment and respite services can put both middle and low income families at financial risk.

“My couple life is totally not existing. My husband has to work all the time so we have enough money.”

“I had to quit working because all my money was going to pay daycare.”

- Emotional strains – In particular, the stress on marital and family life because of the physical, emotional, and financial commitments.

“The first 3 months, we were so tired, we were fighting a lot and didn’t appreciate the kids.”

“The public [health] nurse called me to ask if she could come and weigh the babies. I started to cry. She came right away. My husband was crying on the couch, saying he couldn’t do it anymore.”

- Social isolation – Because of the time restraints associated with raising multiples, many parents have a difficult time getting out of the house.
- Information and Counselling – More multiple-birth specific information and counseling are needed from preconception to childhood.

2. Disparity of Education, Information and Counselling

Recurring commentary was made in relation to:

- Insufficient information on multiple issues and special needs
- Lack of information in languages other than English
- Lack of counselling to help families cope (in any language)
- Lack of education and training for professionals

“I wished I would have known that there were prenatal classes for parents expecting multiples. The regular classes were almost totally irrelevant.”

“I had to look myself for the information I needed, I couldn’t count only on the public health nurse.”

3. Lack of Support

Focus group discussions also highlighted the need for more support as programs which address the singleton population have not met the unique needs of multiple pregnancy, birth, breastfeeding, infant care and respite.

"I still don't understand why I could not receive subsidies for breastfeeding since I was on a special diet because of my child's allergies."

- Respite/Practical help:
 - Few services are available
 - Not enough support available for families with triplets or more
 - The few services that are available are too short
 - Support is not available at needed time (e.g. night)
 - Qualifications are too narrow
 - Services are not coordinated
- Financial:
 - Not much help from government in terms of special UIC or tax credit
- Breastfeeding, Perinatal, Childhood and Youth issues:
 - Often peers or staff are misguided and not knowledgeable enough.
- Special needs (Bereavement, child with special needs, ESL parent, low-income, single, teen or immigrant parents):
 - Parents are not getting enough support and information from peers and professionals

4. Barriers to Access

Our focus groups revealed numerous barriers that limit access to appropriate services, including:

- Lack of services with multiple-birth specific component
- Lack of transportation resources including twin strollers, car seats and/or physical assistance
- Language and cultural barriers
- Location – Families living in northern and rural areas are often isolated from services and support
- Money - Lack of ability to pay for essentials such as clothing, equipment and housing, and services such as respite, in-home help and affordable daycare
- Geographical or social isolation – Families living in rural areas or communities without a MBC chapter are often isolated from services and community support, and have difficulty making connections with other families with multiples for peer support.
- Lack of knowledge about resources such as Multiple Births Canada

5. Advocacy & Public Awareness

- ♦ During the course of the focus groups, it became apparent that the specific needs of multiple-birth families is frequently not recognized by professionals, the general public, or governments.
- ♦ Many families were not aware of Multiple Births Canada or local chapters, or have them confused.
- ♦ Health care providers often do not refer families to MBC or have a misconception about services offered by MBC and its chapters.

RECOMMENDATIONS

The following recommendations are based on ideas generated by focus group participants as ways to effectively support and educate multiple-birth families, service providers and the general public. These recommendations are organized around four major themes:

- Education, Information and Counselling
- Support
- MBC and Chapters: visibility, expectations and reality
- Advocacy and Public Awareness

The following recommendations reflect the thinking and wishes of those individuals who participated in the focus groups. Comments made during focus group discussions confirm that no single intervention will adequately address the issue of multiple births. Just as the challenges identified were numerous and varied, so too must be the prevention strategies.

Education, Information and Counselling

Providing vital and timely information to multiple-birth families is essential to help them cope and make good decisions about parenting. The following recommendations provide guidance to service providers in developing and designing information for these vulnerable families:

1. Fact sheets addressing multiple-birth issues, on paper and on web, and in many languages
2. Guidelines for professionals (multiple pregnancy, bereavement, the early years, special needs, school issues, facts about multiple births)
3. Videos (e.g. preparing for multiples)

Support

The following are recommendations concerning changes needed in the current service delivery systems to better support families:

1. More respite is needed for multiple-birth parents at all levels of government (e.g. public health, home care, doulas)
2. Additional financial support:
 - UIC: double the time or double the money
 - Subsidy for breastfeeding
 - Subsidy for babysitting
 - Subsidy for housing
3. Corporate discount arrangements are needed (e.g. Wal-Mart, Zellers) to help reduce the financial burden faced by families of multiples.
4. More collaboration with community support networks (e.g. having spaces available for multiples in same day-care centre)
5. Better coordination of formal and informal supports (e.g. develop an inventory of services and supports available)
6. More referrals to community supports (e.g. parents of multiples support groups, perinatal networks, non-profits, parent resource centers, thrift stores)

MBC and Chapters: visibility, expectations and reality

Assessing the needs of multiple birth families requires a well-designed, systematic approach used by MBC, at both the national and chapter levels, which is based on collaboration and cooperation. The following recommendations relate to this strategy:

1. More collaboration between MBC and chapters to raise each other's profile
2. Additional publicity and media work
3. Better distribution of brochures describing MBC and chapters services
4. More collaboration with existing community networks (i.e. perinatal, early child development) and government programs

Advocacy and Public Awareness

In order to increase the level of understanding of multiple birth issues and needs among professionals, governments and the general public, which will ultimately improve information, services and supports available to multiple birth families, we need:

1. Guidelines for professionals
2. Guidelines for daycare, preschools and schools
3. Advocacy work towards governments:
 - Revenue: longer UIC (multiplied by number of multiples, prenatal rest: special UIC) and tax credits
 - Immigration: Protocols to help families with multiples
 - Funds for publications of fact sheets in multi-languages
4. Media work to heighten awareness of multiple-birth issues and needs
5. Increase memberships and get funds for subsidized memberships

CONCLUSION

As reported by the many families who shared their experiences, raising multiples can be rewarding as well as very challenging. In order to provide the best information and services for these families and their children, MBC needs the partnership and the financial support from the three levels of government: local, provincial and national. It is only through a collaborative and multisectorial approach that families of multiples will see their basic needs met and their lives fulfilled.