

The CAPC/CPNP Think Tank: Reaching and Maintaining the Focus Population

n March 23 and 24, 2000, the Community Action Program for Children (CAPC) and the Canada Prenatal Nutrition Program (CPNP) sponsored their first "CAPC/CPNP Think Tank" in Ottawa. CAPC and CPNP support a range of community action programs and services for pregnant women and children living in conditions of risk across Canada. The Think Tank was funded by Health Canada under the CAPC/CPNP National Projects Fund, which funds projects that support the objectives of the programs and directly benefit CAPC and CPNP projects across Canada. The model for this unique event was conceived by program consultants at Health Canada, and was then further developed by a team from the Centre for Health Promotion, University of Toronto. (Additional information on CAPC, CPNP and the National Projects Fund is included in Appendix A, and is also available on the Health Canada website at http://www.hc-sc.gc.ca/hppb/childhood-youth/cbp.html.)

The CAPC/CPNP Think Tank brought representatives from 38 CAPC/CPNP projects together with community-based participatory researchers to discuss four important issues of common interest to CAPC/CPNP projects being implemented across Canada. The four issues that were addressed were:

- Maximizing parental involvement
- Reaching and maintaining the focus population
- Factors that contribute to an increased breastfeeding rate in the CAPC/CPNP population
- Partnership and intervention in dealing with child abuse prevention

In order to ensure that the outcomes of the Think Tank were meaningful to CAPC/CPNP projects, an Advisory Committee with representation from projects, as well as regional and national Health Canada staff, designed and shaped the event. This included identifying the priority issues that were addressed during the Think Tank, nominating the researchers who participated in the process, and nominating/selecting projects which had demonstrated innovation and expertise in one of the four issue areas.

The Think Tank resulted in the production of four papers (one on each issue), which integrate the experience and expertise of the project representatives and the community-based participatory researchers. A fifth paper provides an overview of this unique, experimental model and the process that was used to produce the results.

his issue addressed outreach to families that are difficult to reach and involve, such as adolescent parents who are low literacy, transient or homeless, distrustful of services, depressed or isolated. The focus population also includes people living in remote areas; people with low economic resources; those who are involved with the criminal Justice system; pregnant women; and individuals who are involved with treatment centres. The question that participants explored was "What are the basic principles and practices that enable projects to involve hard-toreach families on an ongoing basis?".

What the community said... Learnings

The key question is: "How do we get the focus population involved, and keep them involved?" To answer this, the working group participants identified three key learnings:

- ► It is important to have the right staff.
- ► It is important to have the right recruitment strategies.
- It is important to have the right programs.

These learnings are directly connected to the group's understanding of the complex issues and challenges facing both the focus population and the program practitioners who are trying to help.

"Focus population" is a formal term for people and families who, for many reasons, are vulnerable.

Some participants are there because they have to be. Their participation in a parenting program is mandated by a judge as part of their sentence. Their motivation is fear of losing their children, or of losing the social assistance money they receive.

Sometimes, in small remote communities, families do not get along, and they do not associate with each other. There are also mental health issues, conduct disorders, intergenerational issues, distressful issues and violence issues. Another barrier is shame. People reach a point where they do not want to explain who they are, their low economic status, their isolation or depression, their transience or homelessness.

Some programs working with both Aboriginal and non-Aboriginal people have to deal with tensions between the two groups. There are also issues of cultural sensitivity. What is appropriate for one group may not work for the other.

Given the demographics and the life experiences of the focus population, the Working Group agreed that the underlying challenge is to make the program enticing, so that people feel they want to participate.



"You want to create a safe space – a safe environment where people want to go."

First Learning - You have to have the "right" staff



"People connect to people, not to agencies or programs."

The first prerequisite to reaching the focus population is a committed, value-based, flexible, passionate and fun-loving staff who work from a basis of respecting participants and building on their strengths.

Every day the staff deal with very serious situations. They must understand discrimination. They must understand their roles, what the program is all about, and who they are serving. They must be able to perform serious broad analysis. They have to know how to deal with suicidal people, understand the Court system, and work with different agencies.

Staff must appreciate the importance of language. Positive language is critical, such as "priority parents" and "under-resourced" instead of "high risk" and "no resources". Similarly, literature has to be designed so that participants can relate to it.



"There seems to be a lot of wrong pictures in books – it's always the beautiful family. This does not reflect the reality of the clients."

One Centre has a program called Kick Butt for Two (a name that was chosen by the women themselves). A program that works with pregnant street girls is called "Buns in the Oven".

Sometimes, you have to step back from your own values. The reality is that clients do not always want what you want. It can be challenging to face up to this fact.



"They don't always want what you think they need."



"Don't blame yourself it if doesn't work."

Building on the strengths of participants, staff must be able to advocate for and with participants, and be skilled, flexible and effective in helping people reach their goals.

The project must have a successful staff development program that brings them along quickly, often through very complex situations. Staff training should be built into the budget even though resources are tight. Partnering with institutes in the community can help. For example, Yukon College became a partner for training the care giver.

Staff retention and continuity is important, and is also related to training. If people upgrade their skills and become more qualified, but then do not see an increase in their pay, they may leave.



"Changing staff is bad as you lose the trust of participants. Staff needs to get involved, and this takes time."

Wherever possible, it is good to hire participants, for example, as program assistants, and pay them an honorarium.

Strong leadership is another success factor. The leadership has to be allowing, encouraging, and facilitating. It has to be stressed to staff that they were hired for specific reasons.



"If attracting people is what you want, then you need a happy staff and you need teamwork. You have to dress like the participants, try to blend in, don't wear nametags, and beware of making people uncomfortable."



You can have the best program, but if you don't have the personnel to do it, the program doesn't go.

Second Learning - You have to have the "right" recruitment strategies to "get them there"



"Word-of-mouth is the best way to get more participants. They invite friends."

The most effective recruitment strategy is word-of-mouth. The participants themselves "sell" the program.

As far as the media is concerned, you do not need to be known to the general public, only to your focus population. You should not spend a lot of money to publicize the program in ads.



"We go with the word-of-mouth method, and women just show up and are accepted. It is unethical to advertise programs that are already full."

Instead, you should spend that money on your staff, recruiting, training, etc.



"Waiting lists are a 'no-no' as they just create another barrier. If people have the courage to come through the door or make contact, they should not be put on a waiting list." The location of the program is very important. It must be a community-based location that is accessible to the participants. Alternatively, the staff has to be able to go to the participants.

As well as the physical location, the "space" itself should be welcoming. People should feel that it belongs to them; a sense of ownership is very important. Food is a non-threatening and useful drawing card.



"Our Centre is like a home. They open the refrigerator and help themselves to healthy snacks."



"They cook meals together – food is extremely important. When they are around the table, they tend to be much more open."

Providing on-site childcare can also help to eliminate a barrier to participation.

Simply getting to the centre can be problematic for people with very tight resources, or in remote or rural areas. As most centres have limited funds available for transportation, creative approaches are often required. One centre hired a school bus to bring people to the program. When the bus proved inadequate to meet demand, staff negotiated with the parents to arrange a carpool system. Another program made an arrangement with a local taxi company and provides the mothers free cab rides to and from the program for the first six weeks after the birth of their baby. Some centres provide gas money to help cover travel costs for participants. A back-up plan should be in place to get people to the program.



"We work with two reserves that are located far from each other. It costs as much as \$25.00 one way by taxi to bring participants to the Centre. Over time we have learned to just deal with the challenges (e.g., transportation), and then apply for money to cover the cost."

There is a potential issue of liability in relation to transportation. To avoid problems, in many locations, the parents call each other to arrange transportation so that the agency will not have responsibility. Insurance and liability regulations may vary from province to province.

Confidential and trusting relationships between staff and participants go a long way to attracting people, and to keeping them involved. Problems such as conduct disorders, or Fetal Alcohol Syndrome, can make it more difficult to build relationships. One centre assigns a parent worker and a supervisor to each family that is involved.



"We want our place to be the place where parents want to start their futures again."

Confidence and trust are critical when dealing with mandated services.



"We need to position ourselves with the parents. There is a line and we are on the same side of the line as the parents. We are the ones making the 'link'. Your priority is to be with the parents—the participants. You should always be with them and take into account what their needs are. It is up to us to be their voice."

Personal contact with staff and with peers is crucial for the participants. It is important to keep the activities fun and engaging and to build the relationships between the staff and the parents. Some centres do a lot of home visits to ensure one-on-one contact. Others assign support staff to each family or participant.



"The program is located in an area where families are very deprived. We try to give them the tools to increase their parenting skills. We keep things very informal, and the parents can speak to the Director at any time."

Finally, an important part of the recruitment strategy is to network and build partnerships to involve people. This means letting partners know what your program is about, what it can offer, and to whom.



"I love going to bed on Sunday night because I know that tomorrow I am going to the CAPC program."

Third Learning - You have to build the "right" programs



"If you build it 'for' them, they 'might' come; if you build it 'with' them, then they 'will' come."

Programs that are parent-owned and parent-driven are more likely to succeed. Programs should be customized to meet participants' self-identified needs.

A program should evolve, change and grow with the participants. Some projects have parents on their Boards/Coalitions.

One way to build a sense of ownership amongst participants is to involve them in the evaluation process.



"As much as they dislike doing it [evaluation], it works well. The evaluation results can be used to identify gaps and needs".



"We constantly reassess where we are. We tear down programs. We don't add one, but rather rebuild every year with input from the participants. Our success increases every year."

A centre needs to establish clear goals and objectives and a clear focus.



"The staff needs to have a basic understanding of how population health works. Many agencies have gone too broad. You need to stay focused. You cannot be successful if you have too many programs."

Programs must be culturally appropriate and culturally sensitive.



"Where we live, we have to respect the First Nations' protocol. We are all working together for the sake of the children. Even though we all have different traditions and cultures, we need to respect each other."

A key word is "adapt"; programs should vary from one situation to another. The activities have to be customized to the needs of the group. Staff has to be willing to stretch the boundaries of the program in order to make it fit the participants. One centre has three funded sites in three houses, which makes it very home-like.

One program deals with "street kids", as well as with sexually-abused children and children who need help getting back into school after being expelled. The program also works with children who are at risk of being suspended or expelled from school, and with adolescent/young parents. The key to success in this program is that the children have learned to know and trust the staff. The program adapts to whatever the children want; staff will even go into their homes if invited. Sometimes, a full-day program is set up for the young parents.



"The teen parents love it. They have gone to the pool for the day, camping, on a river boat cruise, to beauty parlours, etc.

Programs should build on strengths.



"I like to let the girls know that anyone can get through the challenges. Eighty percent of the girls I deal with are Aboriginal. These teens work with as many as 13 people on their case. These people do not know them whatsoever and all the teens want is to control their own lives."

Programs should also be creative and fun, and celebrate the successes and milestones.



"Where we live we don't have much to celebrate so we try to make every event a celebration and to highlight the events. The souvenirs, the pictures, the memories are extremely important to the participants. It helps to build their self-esteem. They keep coming back to something nice. Often, it is the small things that become the big things."

One centre has a youth cooking circle program for ten- to twelve-year-old girls, and a group quilting circle. They take pictures of their finished products, as well as pictures of the mothers involved in the programs and keep a photo album.

At one centre, the director takes pictures of the teen mother when she is pregnant, during the delivery, and with her newborn. She then makes a small photo album for these teen mothers.



"We videotape the children's development. We try to start when the mother is six months pregnant and go until the baby is six months old. The mothers love it."



"We introduced the expression 'gentle learning' — a learning that builds their trust and links us to them. We play nutrition bingo. We have a puppet with big teeth and a big toothbrush. They enjoy learning. It is not forced or boring. We teach growth and development in a 'gentle' way. Until you address their basic needs, there will be no learning."

Different agencies also need to support each other.



"We are not all things to all people. You need to know your limits."

It is vital to foster linkages to other resources. What are the other resources that are available? Where else can you go for help? You have to know what is out there.



"We work in partnership with many agencies. Both traditional and non-traditional partnerships (e.g., a motorcycle group) are an asset."



"We are in a community of 1,800 people, and half of the people are Aboriginal. The different organizations work together in the community. We have a coalition meeting every three months, and the parents are invited to attend. Partners meet regularly to share ideas."

Finally, the involvement of fathers can be very important.



"We need specific programs for fathers."

Challenges to Reaching the Focus Population

The working group identified two main challenges to reaching the focus population: resources and capacity-building.

Resources



"I care, but I also have a life."

When you look at all the needs, it is important to priorize them and select a few. Sometimes, there are too many priorities. Projects and programs are always looking for more funds. In order to survive, you have to use creative fundraising, and/or find more than one source of funding.

The ongoing issue of limited financial resources makes it difficult to plan for the future. Who will fund the project?

Limited resources refers to time and to staff, as well as to financial resources.



"I am only funded for 30 hours per week. I find that I don't have enough hours."

Capacity Building



"In order to recruit the public, you need funds. Adequate funding equals better recruitment."

Many centres in remote, isolated or northern settings face particular challenges related to their location. It may be difficult to find skilled people and opportunities for training of participants in the community. Trying to run a variety of programs can be problematic, as each one has a different infrastructure and requirements. To address this, one centre tries to "give ownership" of programs to the community, asking, "what group could best take this on?"

Research Questions

The core question is, "what are the basic principles and practices that enable projects to involve hard-to-reach families on an ongoing basis?" From this, the working group identified three areas of research.

- 1. How do you create an organizational "culture" that supports and respects the values of CAPC/CPNP? The research should address the following factors/elements:
 - hiring and training
 - strong leadership
 - promoting innovation
 - ownership
 - innovation/flexibility
 - funding
- 2. What are the most effective recruitment/outreach strategies for our defined "hard-to-reach" group? There are three distinct levels of activities, all of which are important:
 - individual
 - community partners
 - societal
- 3. How do we adapt/enhance adult learning strategies to meet the needs of "hard-to-reach" groups? The application of "social marketing" techniques should be examined.
 - customize
 - celebrate successes
 - value participants

- need to enhance processes and content to meet specific needs
- keep it informal and let learning roll out.

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Literature Review

What the research says...

Literature Review: Reaching and Maintaining the Focus Population Louise Picard

Introduction

The challenge of reaching and maintaining "hard-to-reach" populations is an ongoing one. Service providers are aware that the people most in need are often the ones who least access programs and services. The growing awareness of the existing inequity in health has added to the debate and the urgency to seek solutions to address this issue. This paper will provide an overview of the issues and possible strategies related to reaching and maintaining the "hard-to-reach" populations.

Benzeval (1995), in his agenda for action on tackling inequities in health in the UK, documents the effects on health of several health determinants such as poor housing, family poverty, smoking, lack of access to services, unemployment, poor education and lack of child care. The model proposed strengthens individuals and communities, improves access to essential services and encourages macroeconomic and cultural change. The solution includes more sensitive and appropriate community-based services with intersectoral links. Several authors in Canada and other countries have documented the health effects of the growing gap between the rich and the poor and society's responsibility to address these issues (Canadian Council on Social Development, 2000; Health Canada, 1999; Stewart, 1990). The Early Years Study (McCain et al., 1999) notes the challenge of reaching "at risk" populations within global programs and the need for active outreach. Clément (1990) reviews social policy in Quebec and the need to put energy and finances into targeting those that are most in need. Torjman (1998) presents a global view in a model for community level interventions that targets community-based poverty reduction. The key interventions are: meeting basic needs, removing barriers, building skills and promoting economic development. Many of the solutions are at the macro, social policy level and although all service providers have a role to play in terms of advocacy and influencing system level change, this dimension is beyond the scope of this review.

Service providers from many sectors have shared and deliberated possible approaches and strategies that might work. Increasing skills and knowledge around reaching "hard-to-reach" populations was the theme for the 1999 Ontario Heart Health Conference (Heart Health Resource Centre, 1999) and a similar topic on how to provide prenatal care for women at risk was the theme of a series of American consensus conferences in 1987 (Cagle, 1987). The Ontario Healthy Babies and Healthy Babies Program are planning a fall workshop in the Fall 2000 on exactly this topic. The fact that there is an entire journal in the US devoted to the topic: The Journal of Health Care for the Poor and the Underserved again attests to the attention, challenge and limited success in dealing with this issue.

Methods

Recognizing the scope of this topic, a comprehensive literature review addressing the issue of reaching and maintaining the focus population was not possible. First is the challenge of defining "hard to reach". This same issue also generated a lot of discussion during the recent Ottawa CAPC/CPNP Think Tank exercise. For that exercise, "hard-to-reach" had initially been defined

as including "parents who are teenage, low literacy, transient/homeless, distrustful of services, depressed or isolated" The Think Tank group added other sub-populations such as "families facing financial barriers" and "rural families". In retrieving the literature, it became apparent that there are numerous publications on each of these individual topics and groups. In addition, other "hard-to-reach" groups were identified in the literature such as the inner-city urban population who are seen as facing unique barriers related to accessing service (Black et al., 1998).

Decisions therefore had to be made which limited the search, recognizing that the overall review would not be exhaustive. The search strategies used were as follows: on-line computer searches of selected databases, a hand search of selected year 2000 journals, limited Internet searches of SANTECOM for Francophone resources and reviews of references lists of articles. The on-line search included: MEDLINE, CINAHL, ERIC, PSYCHABS, and included the years 1995 to 2000. Several older articles, as identified by reference lists, were also retrieved. Key search words included: poverty, public assistance, homeless (persons), transients and migrants, social class, ethnic groups, educational status, low literacy, minority groups, rural environments, lower income level, disadvantaged, marginalized, socio-economic status. All Francophone and Anglophone publications were included.

Using the above search strategy, a total of 152 articles, books or reports were retrieved and reviewed for relevance. A total of 87 relevant articles received a more in-depth review and key points as they pertain to this article and defined focus population were summarized. The potential literature on this topic is impressive since it encompasses articles dealing with a wide range of programs targeting all age groups from prenatal to seniors. This review is largely limited to literature dealing with approaches used with the prenatal population and those targeting families with young children. A few more general articles however, which offer broad concepts or potential models, have also been included.

A few issues arose out of defining the search strategy. One is that the terminology selected to identify the "focus" population does in some cases reflect certain philosophical and political differences. The Think Tank referred to the focus population as the "hard-to-reach". Various terms used in the literature include: the disadvantaged, the underserved, at-risk populations, vulnerable populations. There is some debate in the literature about using terms like "at risk" or "disadvantaged" which have a negative "disempowering" connotation especially when the approach in working with this population should be one of empowerment (Clément, 1990). These authors argue that some of the current terminology, in some cases, is an example of using a new expression for an old reality - poverty. These authors propose an ecological model of "risk" as opposed to an individual model.

Another key issue which had implications for the review is the fact that there are two components to working with the "hard-to-reach" – one is reaching or recruiting families and the second is maintaining them. Sarah Brown (1988; 1989) in an older but thought-provoking article and committee report entitled <u>Prenatal Care: Reaching Mothers, Reaching Infants</u> discusses the ethics of trying to improve our recruitment of "at risk" pregnant mothers if the system cannot or will not be responsive to their needs.

This literature review did attempt to include both concepts – reaching AND maintaining the "hard-to-reach", recognizing the limitations of trying to include all the elements that make a successful program accessible, available and acceptable for "hard-to-reach" populations.

Findings

Barriers

Gaining an understanding, by service providers, of the barriers faced by "hard-to-reach" families is proposed by some authors as a first step in addressing existing barriers. Some researchers have also suggested that there are differences between the parents' and providers' perceptions of barriers in accessing services (Salsberry et al., 1993), with providers sometimes clearly underestimating system barriers faced by parents.

The literature also offers several models or classifications that are useful when considering barriers and the practices that enable projects to overcome these "hard-to-reach" families. Generally, these fall into the individual, interactional or system/structural groupings with some variations. Various authors define them differently, but generally, the individual barriers deal with personal beliefs, attitude, lack of time and energy, while the structural barriers deal with accessing service and system issues. The interactional barriers deal with receiving quality care and provider-client relationships.

There are several retrospective studies which asked women post-delivery to identify barriers that prevented them from getting prenatal care. Several American authors (Poland et al., 1987); (Kalmuss et al., 1990); (Harvey et al., 1993); (Aved et al., 1993); (Scupholme et al., 1991) interviewed disadvantaged women during the postpartum period and identified perceived barriers. Some were *personal barriers* related to attitude and motivation including attitude toward the health professional, delay in suspecting pregnancy, depression, substance use and others were *structural barriers* such as accessibility, financial barrier and lack of system support. The authors proposed solutions often centered on augmenting, simplifying and coordinating services and developing population specific outreach for "at risk".

Kelley (1992) described the perceived barriers in the use of a comprehensive prenatal program by interviewing 177 black women in high-risk communities. Perceived barriers included "convenience factors" such as job demands, travel time and child care as well as provider-patient interaction barriers including lack of provider respect and inadequate time with provider.

Brown (1989) also reviewed barriers to prenatal care within the American health care system and suggests the categories below. It should be noted that these reflect an American social policy and institutional perspective.

Sociodemographic barriers: e.g., poverty, residence, minority status, age groups, etc.

System—related barriers: e.g., financial, transportation, child care, poor service coordination, language, limited service hours, negative attitude at clinics

Attitudinal barriers: e.g., fear of doctors or procedures, unplanned pregnancy, fear of deportation or discovery of pregnancy, etc.

Consequently, the authors recommendations to improve participation in programs by "hard-to-reach" populations included: reducing financial obstacles, expanding capacity of existing services, improving institutional practices to make services more accessible and acceptable to clients such as atmosphere, clinic procedures, active case finding and outreach and provision of support to encourage continuation of care.

In a Canadian prenatal study (Picard et al., 1998), 399 pregnant adolescents were interviewed. Several themes related to barriers to positive behaviour change were identified. These included personal barriers such as personal stress including fear, guilt and ambivalence and system stress related to provider attitude and access issues, financial barriers, peer and family behaviour and knowledge level/misconceptions. Outreach barriers were also identified and the use of multiples strategies for reaching pregnant adolescents was recommended (Vaillancourt et al., 1999).

Another American study explored barriers identified by low-income parents in the use of the Early Periodic Screening, Diagnosis and Treatment Program for children. This program provides health care at no cost and with transportation support. Recognizing that these studies are in the American socio-political context, a consistent message was that removing financial barriers is only part of the solution. Parents interviewed identified the following additional main barriers: competing family and /or personal issues and priorities, perceived or actual system barriers, and issues related directly to problems with outreach effort. Other barriers were long waiting times, transportation and disrespectful care. Recommendations included enhanced parent focused outreach through a variety of venues, system changes such as hours, location, use of incentives and attitudinal changes.

A study, related to the same program, evaluated three outreach interventions to increase the use of the program (Selby-Harrington et al., 1995). They concluded that briefly informing families was not effective whereas interventions, letters, phone calls or home visits produced more screening but ultimately minimal impact. Using traditional methods to reach disadvantaged families may need to be reconsidered. Knowing about the service is but a small part of the equation; supports and system change are also needed.

The article by Farley-Short et al. (1992), reiterated the American message that Medicaid and finances explain only part of attendance for regular well baby visits and urges bringing services to the children in day cares, welfare offices, etc. Several studies emphasized that reducing financial barriers is not enough. For instance, Friedman's commentary on policy perspectives (1994) made this point and raised the issue of unconscious barriers such as attitudes related to race, culture and access issues in rural vs. urban contexts.

Melnyk (1988, 1990) offered a critical review of the literature regarding barriers to care and proposed a classification of *structural barriers and individual barriers*. Based on a survey of professionals and university staff, he proposed five categories: provider-consumer relationships, site –related issues, cost issues, fear and inconvenience factors.

Other studies offered a broader perspective on barriers faced by disadvantaged women generally. Sword (1997) provided an excellent review of the literature and explained important determinants of health-related behavior among socio-economically disadvantaged single mothers. She used a health promotion model to identify 1) intrapersonal factors such as lack of time and energy and money, perceived self-efficacy, depression; 2) interpersonal processes such as social isolation, values conveyed by their networks; 3) institutional factors which includes structural factors and relationships with service provider, previous system experience as dehumanizing; 4) community factors such as concentration in "high risk" neighbourhood, housing quality; and 5) public policy such as the social, political and economic patterns of a society including child care policies.

Graham (1990) offered an insightful discussion in her exploration of health behavior in poverty for women. This article helped to reframe health behavior choices for women caring for children in poor families. This appreciation of the broader sociopolitical issues that shape the lives of low-income single mothers is essential. She encouraged the worker to enter into a dialogue and partnership with families concerning their perceptions of need and structural changes that would improve their lives.

Several qualitative studies elaborated on the personal barriers faced by certain "hard-to-reach" populations. The findings from several of these studies highlighted the fact that disadvantaged populations do not have the time and energy for health-seeking behaviour. Browne (1995) in her working paper on the resilience and vulnerability in mothers and children on social assistance presented the results of interviews with 101 sole support female parents on social assistance. Forty-five percent had a major depressive disorder and almost half of those had a superimposed milder yet unremitting type of depression, therefore facing a "double depression". The implications for accessing services are illustrated in the fact that people with double depression used fewer ambulatory, counseling or psychiatric services but higher hospital service. Although the numbers are small, those without depression listed as job training and child care as the services they most want while those with double depression wanted counseling.

Olson and Banyard (1993) asked 52 low income single mothers of young children to keep a daily journal writing about the stresses they faced and the strategies they used. Their goal was to capture the strain of poverty and single parenthood. Main stressors were child-related such as dealing with negative/challenging behavior, followed by interpersonal stressors (family/boyfriend) and financial stressors. A Canadian study collected data by using focus groups and interviews on the job-family strain among employed single mothers of preschoolers (Campbell et al., 1992). They document the work strains such as attitude to employment, work time and work satisfaction and the family variables such as number of children and ages and income adequacy. They cautioned that these mothers are not homogeneous, (e.g., never married vs. divorced) but that taking programs to the mothers in work and day care settings and facilitating support networks should be considered.

Sokoloski (1995) in qualitative interviews with Canadian First Nations women explored their beliefs about pregnancy and from the derived themes recommended non authoritarian, individualized and unhurried care as a strategy to address perceived organizational barriers.

In a second project with primarily aboriginal women, Woodward and Edouard (1992) described a Canadian project, which reached out to urban Aboriginal people and other high risk pregnant women in their community. They identified low income and the alienation from traditional health services as two key barriers. Largely descriptive in nature, this project stressed the importance of reaching out such as the involvement of Aboriginal community health workers and the need to make contact with key individuals and agencies involved with this target population in order to engage them in the development and implementation of the program. They proposed that the establishment of an Advisory committee with representation from Aboriginal women leaders offer both credibility and source of referral to the program.

Another sub-population that is identified as having special needs are rural families (Williams et al., 1997). Lapointe, (1989) provided a descriptive analysis of their project which sought to bring prenatal and early childhood services to a rural area in Quebec. They talked about an "invisible

boundary" which presents a challenge in having a program "take root in the rural community and system change required to make that happen. They discussed the importance of the provider's need to establish credibility and to demonstrate respect for the potential in the community. By gaining better understanding of the setting and its social organization, it will enable projects "collés sur la réalité des communautés" (to stick to the reality of the community) (p.95).

Some descriptive studies dealt with specific "hard-to-reach" populations such as the homeless (Norton et al., 1995) and discussed their access issues and special needs, stressing the importance of dealing with the current crisis issues which may lead to readiness for health promotion. The importance of addressing social policy issues is underscored. Berne et al. (1990) offered a theoretical model for addressing the health needs of homeless families and reiterated some of these key issues. Pomeroy and Frojmovic (1995) offered an inventory of programs targeting the homeless in the US and Canada.

Several publications such as Huff and Kline (1996) offered frameworks for planning services for multicultural populations (Battaglini et al., 1997). The importance of needs assessments, tailoring resources and programs, and recognizing diversity among this sub-population are mentioned. The need for practitioners and staff to develop "cultural competence" is stressed.

Literacy and numeracy skills are essential. "Hard-to-reach" populations may have difficulty participating fully in the community. People with low literacy skills often feel alienated and have difficulty finding and accessing health information and services. As a result, they suffer poorer health than those who have higher literacy skills (Health Canada, 1999). The Canadian Public Health Association's National Literacy and Health Program (2000) is in its seventh year. It continues to raise awareness about the importance of clear verbal communication and plain language in health professional practice by providing resources to help health professionals serve people with low literacy skills more effectively.

Overall, several authors offered us an understanding of the barriers and an insight into the beliefs and realities faced by several sub-populations within the "hard-to-reach" focus population. Although many of their individual realities and issues may be different, there were overall general categories proposed which may be useful in considering barriers and strategies to be considered in working with this population: 1) socio-demographic barriers which include financial, place of residence (urban, rural), language 2) individual barriers which include personal beliefs, attitudes, life crises 3) interactional barriers such as provider-client relationship respectful of culture and life circumstance and 4) system barriers such as access issues, transportation, child care, long waiting lists, etc.

One author also suggested using the PRECEDE-PROCEED health promotion planning model in considering barriers. Brink et al. (1989) examined a hospital-based infant safety seat program for low income families. They used the PRECEDE-PROCEED model to identify the factors that come into play. These factors included: the predisposing factors such as mother's knowledge, the reinforcing factors such as social support for use, and enabling factors such as finances or use of public transport.

Effective Strategies

Descriptive and observational studies reflect the fact that there has been much innovation and creativity in trying to improve efforts to reach and maintain involvement of the "hard-to-reach" population. One example is a program for pregnant adolescents that actively involves the baby's grandmother in the intervention. (Roye et al., 1997). Unfortunately, the rigor of the evaluation is such that there is no evidence to demonstrate its effectiveness as a strategy. This is frequently the case in much of literature that was reviewed. Useful insights and ideas have been generated but there has been very little evaluation to determine which of these approaches work. However, as mentioned in several systematic reviews on related topics, the complexity of some interventions presents a challenge to rigorous evaluation and makes it difficult to evaluate components within the program. Lazenbatt (1999) in assessing the contribution of nursing initiatives to improving the health of disadvantaged women in Ireland offered evidence from 22 case studies and defined eight characteristics of effective programs. They argued that although these qualitative reports did not meet the criteria of systematic reviews, they offered valuable information. They recognized that more rigorous evaluation is needed in the future. This section will highlight some related systematic reviews as well as other findings which may contribute to our understanding of possible effective strategies.

One Canadian article (Loos et al., 1996) offered a 15-year review and critical analysis of the literature exploring what determines an effective prenatal program for pregnant adolescents. The four themes that emerged were that adolescents want information that is consistent with their needs, values and beliefs (and that health professionals may be unaware of what these needs are), appropriate to their stage of development, provided in a sensitive, caring manner and that offers economic and psychosocial support such as nutritional supplements, transportation, opportunity for social support. Elements associated with effective strategies for this target group include use of multidisciplinary teams, community involvement and school-based programs for ease of access.

Some of the available evaluations related to strategies to promote health with disadvantaged communities and target very specific programs such as bicycle safety or use of car seats. Many of these studies are methodologically quite weak or it is impossible to differentiate which components contributed to the success. For example, in the program evaluation of a bicycle safety promotion among low-income preschool children (Britt et al., 1998), free helmets were provided to the children as well as interventions in the classroom and with families. It is impossible to determine whether the free helmets alone accounted for the pre-post differences observed.

Related systematic reviews

There are however a few systematic reviews which are pertinent to this topic. They summarize what is considered the best available research evidence after a comprehensive search strategy and quality assessment of each study. These reviews are largely limited to controlled trials which are felt to offer the strongest evidence that a strategy works or doesn't. Descriptive reports or observational studies are generally not included.

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One review from the United Kingdom summarizes the research on the Effectiveness of Health Service Interventions to Reduce Variations in Health (Arblaster et al., 1995). As the authors mention, the diversity of interventions, settings, populations and outcomes do limit the quantitative synthesis of the results. The review does include several studies dealing with strategies related to reducing inequities in prenatal and child health but also includes studies on injury prevention, heart health, and a variety of other topics. The authors conclude that removing financial barriers to accessing health care can make an important difference to reducing variations in health but that in itself is not sufficient. Several previously mentioned studies have also made this point. The review suggests that a broad spectrum of services crossing traditional professional and other boundaries and that are intensively carried out are most successful in reaching and helping the most disadvantaged. However, the successful complex interventions can rarely use study designs that tell us which components of the intervention make it successful. The High/Scope Perry Preschool study is one example (Schweinhart et al., 1993). However, based on the findings, the review does offer a useful checklist of points to consider when designing an intervention to reduce variations in health. The four areas they propose be considered are:

- 1) the messages/actions delivered, e.g., Will members of the target group be involved in the design, implementation of the message? Are the intended messages acceptable to the target group?
- 2) the setting, e.g., Where might the intervention be most appropriately delivered? How homogeneous is the population of interest?
- 3) individual delivering the intervention, e.g., Who might be the most appropriate person/group to deliver the message/actions? (health professionals, trained peers, community volunteer, etc.)
- 4) support material/resources, e.g., Would the provision of assistance with transport and/or child care make it easier for members of the target group? How appropriate are the written or audio-visual material? (p. 35)

Arblaster et al. (1996) in a follow-up article on this same review offers additional insights. The findings from the 24 effectiveness studies and previous reviews identified some of the characteristics of successful interventions for this focus population. They included: systematic and intensive approaches to delivering health care; community commitment; improvement in access and prompts to encourage use of services; strategies employing a combinations of intervention and those involving multidisciplinary approach; prior needs assessment to inform the intervention design; face to face interactions; ensuring interventions are culturally appropriate; the importance of the agent delivering the intervention and use of outreach workers or peers; and training of those agents; provision of material supports and resources and the involvement of peers in the delivery of the intervention. Recognizing that the most significant contribution to reducing health inequalities will be in improving economic and social conditions and physical environment, there are interventions nonetheless that can contribute to that goal.

A similar European review (Holland et al., 1997) looks at interventions to reduce socioeconomic health differences. Interestingly they included few American studies since the findings are often felt not to be relevant to European social reality. They conclude that providing information alone is mostly effective in higher socio-economic groups and that information and personal support are more effective with lower socioeconomic groups. They identify three types of interventions;

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structural ones which target the determinants of health, interventions within existing curative or preventive programs and thirdly, health education and health promotion approaches. They conclude that although the interventions demonstrate a lot of initiative, the evaluation is too limited to allow a recommendation as to policy for reducing socioeconomic health differences. In addition, they add that health education and promotion strategies appear to be successful if they include support and structural measures.

Three Canadian systematic reviews undertaken by the Public Health Research, Education and Development (PHRED) Program in Ontario are also pertinent to this project. One of the conclusions of the review on the effectiveness of parenting groups with professional involvement in improving parent and child outcomes (Thomas et al., 1999), is that incentives such as child care and reimbursing transportation costs increase program accessibility for all parents and also that collaboration between public health and other relevant community agencies should exist to provide programs for families at risk for poor child developmental outcomes. The review on the effectiveness of home visiting as a delivery strategy for public health nursing interventions to clients in the prenatal and postnatal period (Ciliska et al., 1999) also identified the value of partnerships in that the most effective interventions involved community agencies and primary care services. Multiple intervention strategies were most effective and these home visiting interventions with women who were at high risk due to social circumstances, age, income or education had greater impact that those directed to more advantaged clients.

The third PHRED systematic review outlines the evidence for the effectiveness of peer/paraprofessional one-on-one interventions in promoting positive maternal (parental) and/or child health and developmental outcomes (Wade et al., 1999). This review offers a good summary of the evidence to date. In searching the literature for this article, several studies were retrieved which offered descriptions of programs for "hard-to-reach" populations using peers, or para-professionals without including an evaluation of its effectiveness. Some of these are of interest since they suggested creative approaches or target populations that are infrequently studied. For example, McFarlane (1997) in describing a program to reach pregnant abused women proposes that the use of "mentor mothers" assists in dealing with some of the barriers faced by this particular population. This included their high transient rate (moving six to eight times in their pregnancy) and the fact that locating these mothers for initial and continued contact was "difficult and labour intensive". Several articles present largely observational research or relatively weak study designs (e.g., high drop-out rates, retrospective designs, etc.) relating to the use of non-professionals to reach "high risk" prenatal populations such as disadvantaged pregnant adolescents (Julnes et al., 1994; O'Sullivan et al., 1992), inner-city black population (Graham et al., 1992; Poland et al., 1992) or ethnic populations (Parsons et al., 1992). Some of the stronger studies dealing with use of para-professionals with high risk families with young children (Field et al., 1980; Johnson et al., 1993) are included in the Wade review.

In the Wade systematic review, almost all scientifically sound studies in this review targeted "high risk " populations and many were part of an intervention with multiple components. Evidence suggests that peers/paraprofessionals can have a positive impact on child development and parent child intervention, particularly when the intervention is of high intensity beginning in the prenatal period and the peer/paraprofessional intervention is embedded in a multifaceted intervention. The long-term effectiveness of these interventions has not yet been established. One recommendation is that peers/paraprofessionals should receive training in promoting child

interaction, child development and the peer-paraprofessional role. They should also receive ongoing professional supervision.

A Cochrane Collaboration systematic review on home-based social support for socially disadvantaged mothers (Hodnett et al., 1999) concludes that postnatal home-based support programs have no known risks and may have important benefits for socially disadvantaged mothers and their children. Programs which capitalize on the skills of experienced mothers may be less expensive and culturally sensitive than purely hospital-based programs. This finding is similar to the results of a descriptive study using lay home visitors in a smoking cessation program for "hard-to-reach" urban community (Lacey et al., 1991). They credit the success of their program with the use of influential, local members of the target group as change agents within the program.

Lapierre et al (1995) offer a theoretical framework for prenatal peer counseling based on a program in the province of Quebec. They propose that using peer counselors is an empowering strategy that addresses barriers to prenatal service such as attitude of women toward health care and professionals, fear and power issue (e.g., taking their children) and strained relationships which may lead to values conflict which in turn violates empathy, respect and acceptance.

In addition to the use of peers and para/professionals in dealing with interaction barriers, other strategies are also proposed. Strickland (1996) in an exploratory study in a medical care setting examines the barriers to provider-client relationships for low income black households in rural southern U.S. He makes suggestions to enhance that relationship including relevant staff training which includes multicultural empowerment issues and increasing knowledge and respect for other cultures.

There are many relationship models in the literature but these are beyond the scope of this review. Some models are specific to health promotion with mothers and children. For example, the COACH model proposed by Hanks et al (1995) seeks to translate theoretical models into practice for nurses visiting low-income mothers in assisting them to change health-related behaviors. The acronym COACH captures the central elements of the approach: C - Caring, O - Ongoing development of the mother and relationship A - Action, fostering mother's active participation, C - Context, understanding and respecting the mother's culture and life situation H - Harmony – seeking harmony between values, goal and behaviours.

An evaluation of an early intervention program for Québec children at high risk, Apprenti-Sage, also offers insights into client-provider relationships. The authors conducted interviews with mothers to determine their satisfaction with different elements in the program (Piché et al., 1995). Although, the numbers are small (n=17), many of their comments are consistent with several models presented. For example, they expressed appreciation for the transportation, sharing with other parents, etc. Of interest, is that many of their comments related to the family-provider relationship. They expressed satisfaction for the competence, support, devotion and trust of the providers but had concerns with too great an intrusion into their personal lives and a perceived competition with their role as mothers if there were strong provider-child emotional ties.

Also in Québec, there are other programs, primarily prenatal, which have demonstrated success in reaching the "hard to reach" populations and offers lessons learned including the challenge of addressing interactional barriers. Examples are the Montreal Diet Dispensary which has served as

model in Canada (Higgins et al., 1989). The OLO (Oeuf- lait-orange) project is another prenatal project which also targets women who are facing financial or social difficulties (Leduc et al., 1989). They attribute the program's success in part to the fact that the provision of eggs, milk and oranges meets a basic need – to feed oneself and acts as an incentive. But, they also stress that the personal qualities of the staff and their ability to reflect on their practice and their values is a key element. They offer some insights as to the elements of trust and effective relationship in this context and identify the training and support of the workers along with strong staff development program and opportunity for team meetings as key. Other recommendations for success include stable financing, the use of community workers and well-defined program objectives.

In a Canadian study on approaches for tobacco reduction with disadvantaged prenatal clients (Browne et al., 1990), the focus is also on the interaction, that is the provider-client relationship, and stresses the importance of a relationship that is "respectful of client's life circumstance and socio-cultural orientation". The authors advocate for a solution-focused approach which incorporates principles of empowerment. Although there were serious limitations to the evaluation of their program such as a very high drop-out and a primary focus on process evaluation, the proposed approach to interviewing and counseling is of interest and consistent with several other studies.

There are numerous studies which propose a variety of strategies at the individual, interpersonal and system level. However, many are based on the experience of their program and lack evaluation data. Another pertinent example is a model proposed by Nugent (1988) for providing promotion to children from low-income, ethically diverse backgrounds. Suggestions to use individualized approaches to meet specific needs, respect traditional healing practices, flexibility in scheduling to assist with dealing with multiple stressors, bring service to the community.

Conclusion

The numerous program descriptions offer many valuable and innovative ideas for possible strategies. Some have been used for specific sub-populations and that should be taken into consideration. The pertinent systematic reviews and effectiveness studies offer useful guidance as to effective interventions with this focus population. It must be kept in mind that this review is limited in its scope, in part because of the topic and in its depth – the initial search was for the last five years.

Nonetheless, it is useful to consider some of the consistent findings on possible effective strategies. Elements of the barriers' framework may be helpful here since most strategies fall within the: interactional, system and social policy approaches. If we also include the two aspects of this project which include both reaching and maintaining the focus population, we could add as proposed by some authors, a category of "outreach" strategies which support the "reaching out" component.

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Based on the findings of this review, some of the possible strategies suggested could include:

Outreach: It is suggested that outreach strategies for this population be multifaceted and active. It may be labor-intensive and at times difficult since these families face many competing demands and high transiency rates have been reported in several sub-populations. The use of concrete incentives or effort to meet their immediate needs has also been shown to be effective.

Interactional: The characteristics of the staff and service providers are key in the success of the program. These include being respectful and sensitive to the clients' culture, beliefs and life situations, and offering support. Staff training and ongoing staff development dealing with issues of helping relationships, and cultural understanding would seem to be indicated. The use of peer and para/professionals within the contexts described in the effectiveness reviews appear to be effective strategies with disadvantaged populations. The use of multidisciplinary approaches has been suggested as criteria for success by several authors and within several systematic reviews.

System: There appears to be good evidence that addressing financial, transportation and child care issues increase program access. Other considerations include bringing services to the clientele (the setting), ease of making appointments, flexibility, waiting time etc. Basing interventions on identified needs, involving participants and improved coordination and integration of services have been identified as key elements.

Socio-demographic/social policy: In keeping with the socio-environmental approach to health, rather than focusing on high risk populations, it is also important to focus on high risk conditions (Anderson et al., 1996). The strategies here are broad and encompass empowerment and advocacy included in a community development approach.

The findings from this review summarize some of the literature on barriers and possible strategies for reaching and working with hard-to reach populations. This will hopefully offer a useful context within which to add the additional findings from the consultations with the experts in the CAPC/CPNP field.

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CAPC/CPNP Think Tank 2000

Common Themes and Observations

Common Themes and Observations: CAPC/CPNP Think Tank 2000

Each Think Tank Working Group addressed a specific issue, and identified "learnings" relevant to that issue. These learnings are reported, in the language of the participants themselves, in the individual Working Group reports. The hope is that these will provide insights, ideas and guidance to other CAPC/CPNP projects that are dealing with similar issues and challenges.

In addition to project representatives, each Working Group included an academic researcher with a particular knowledge of and expertise in community-based research. The role of the researchers was to link the experience-based learnings identified by the project representatives with broader, research-based findings drawn from well-known and well-respected national and international sources. Thus, each Working Group report is supplemented by a "literature review" conducted by the researcher following the Think Tank.

Over the course of the two-day Think Tank, project representatives emphasized that each project had its own dynamic and unique flavour. The culture of the local community, the demographics of the target population, the specific needs and life experiences of the participants (and of the staff) – factors such as these affect the way each project is designed, how it works, and what it achieves. In the context of a community-based project, the representatives cautioned, the critical success factors are *flexibility* and *adaptability*. A cookie-cutter, rigid methodology just does not work.

At the same time, however, a number of common themes and elements are evident throughout the four Working Group reports, regardless of the specific issue under discussion. These same themes and elements are identified in the literature reviews conducted by the individual researchers. Clearly, there is validity and consistency to the approaches and strategies of CAPC/CPNP projects across the country.

Some of these shared observations and themes, with representative supporting literature references, are summarized below. Please note that the themes are not "ranked" to reflect any order of significance.

Common Themes and Observations	Representative Supporting Literature*
Flexibility and adaptability: in program development, in project management, and in evaluation criteria and methodology	 Gaba & Lincoln,1990 Allard, 1993 Massé, 1993 Smith, 1994 Fetterman, 1996 Hembrof et al., 1999
Recognition that it takes TIME: to build confidence and trusting relationships, to make progress and achieve and measure results	▶ Guba & Lincoln, 1990▶ Allard, 1993
Commitment to "partnership" approach: parents/families as partners; also, partnership with other agencies, and with other people in the community (e.g. businesses, media, churches)	 ▶ Kiefer, 1984 ▶ Freed et al., 1992 ▶ Bernstein et al., 1994 ▶ Peters & Russell, 1994 ▶ Hooper-Briar, 1996 ▶ Servian, 1996 ▶ Barter, 1998 ▶ Howell, Devany, McCormick, Raykovich, 1998 ▶ Le Bossé et al., 1998
Continuum of services and programs	 ▶ Goffin, 1983 ▶ Carniol, 1995 ▶ Le Bossé, 1998 ▶ O'Donnel et al., 1998 ▶ Rifkin et al., 1998
Governance; direct involvement and empowerment of participants in all aspects of the program, from program development to decision-making and evaluation processes	 Dunst & Trivette, 1987 Berkowiyz, 1990 Rodal & Mulder, 1993 Lee, 1994 Pantoja & Perry, 1995 Bellefeuille & Ricks, 1997 Waler, 1998 Barter, 1999

Common Themes and Observations	Representative Supporting Literature*
Values, principles, and attitudes of staff; strength-focused and family-focused; non-judgemental, positive language and terminology	 Bracht & Gleason, 1991 Smale, 1995 Saleebey, 1996, 1997 O'Donnel et al., 1998 Robbins, Chatterjee & Canda, 1998 Arcury et al., 1999 Seita, 2000
Staff retention, continuity	► Noted in all papers, but not specifically referenced
Adequate and appropriate levels of resources (human, financial, in-kind)	 Callahan, 1993 Ozawa, 1995 Schorr, 1998 Arcury et al., 1999 Seita, 2000 Waldfogel, 2000, 1998
"Fun": celebrate successes, participate in special family events, creative activities relevant to target groups	 Carpenter, 1990 Bracht & Gleason, 1991 Landerhold & Lowenthal, 1993 Mattiani, 1993
Open-door, friendly, non-threatening, home-like environment/space	► Scorr, 1998 ► Barter, 2000
Accessibility of the program: location, transportation, child-care, home visits, on-site visits	 ► Thomas et al., 1997 ► Altpeter et al., 1998 ► Lauder, 1998 ► MacDonald, 1998 ► Arcury et al., 1999 ► Ciliska et al., 1999

Common Themes and Observations	Representative Supporting Literature*
Culturally-appropriate and socially-appropriate programs, services (this referenced Aboriginal communities; but also isolated, Northern, rural communities, and target populations with specific problems and needs such as FAS, single parents, abusive relationships, also illiteracy/poor literacy levels, and so on)	 ► Taylor-Henley & Hudson, 1992 ► Morrissette et al., 1993 ► CCSD, 1995 ► Norton et al., 1995 ► Red Horse, 1995 ► Barter, 1996 ► Huff & Kline, 1996 ► Loos et al., 1996 ► Strickland & Strickland, 1996 ► Battaglini et al., 1997 ► Holland et al., 1997
Peer support, mentoring programs	 ▶ Parsons et al., 1993 ▶ McFarlane et al., 1997 ▶ Orrell-Valente et al., 1999 ▶ Wade et al., 1999
Education, training and development opportunities, for participants as well as for staff/workers	 Lowe, 1990 Crowder, 1991 Westphal et al., 1995 Davies-Adetugo & Adebawa, 1997 Beshgetoor et al., 1999

^{*} The references identified here are <u>representative only</u> of the sources identified by the academic researchers who worked with each Working Group on the four issues discussed. It must be emphasized that each researcher provided extensive bibliographies of source material. These bibliographies are included with the Literature Reviews appended to each Working Group report.