Health and Health Care for the Residents of New Brunswick: Focus Group Perspectives

A Report of the New Brunswick Community Health Assessment

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Working Together, Living Healthier

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"Working Together, Living Healthier"
Trabajando juntos, vivimos más sanos

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Table of Contents

Health and Health Care for the Residents of New Brunswick: Focus Group Perspectives

Peter Guarnaccia, Igda Martinez, Mina Silberberg, Joel C. Cantor, Denise Davis

EXECUTIVE SUMMARY

From May of 2002 to May of 2003, Rutgers Center for State Health Policy conducted 12 focus group interviews in New Brunswick with 110 residents from different sectors of the community and with front line health and social service providers. These interviews comprised the third stage of a community health care needs assessment being conducted as part of the Healthier New Brunswick 2010 campaign – a campaign designed by New Brunswick Tomorrow to engage community leaders in developing and implementing a long-term strategy to improve the health of the residents of New Brunswick.

The goals of the interviews were to identify key health problems in New Brunswick from different sectors of the community and to identify possible solutions to address these problems from the perspectives of community residents and front line service providers. Towards these ends, respondents were asked to identify the major health problems in New Brunswick; to assess the major strengths and resources in New Brunswick to address problems of health and health care; to identify health resources that could be used more effectively; and to suggest strategies for improving the health of New Brunswick's residents.

The major issue that emerged in all the focus groups was access to health care. Participants identified a wide range of access issues and made it clear that access is a complex problem in New Brunswick. While many of the standard access issues such as lack of insurance and transportation problems emerged in the discussions, there were a wide range of access problems that do not usually surface in discussions of access to health care. Particular barriers to care that were emphasized were the lack of health insurance, the large number of undocumented residents and the lack of bilingual/bicultural personnel in the health care system. Health education about both the major health problems and how to navigate the health care system were significant issues. The majority of the focus groups identified the central role of the Chandler Health Center in addressing the health needs of the community. They also noted that Chandler was often overwhelmed by the needs for health care of the city's residents and the lack of alternative primary care resources.

The health problems most frequently identified by respondents were: 1) oral health problems in children; 2) alcohol, drug abuse and sexually transmitted infections among the teen population; 3) diabetes and high blood pressure as ubiquitous health problems in adults; and 4) depression as a serious mental health problem for adults and the elderly.

Based on these findings and on the suggestions of the key informants themselves, the report provides the following recommendations:

- Expand Community-Based Primary Health Care Services
- Improve the cultural competence and language capacities of health care programs and providers
- Expand school based health resources
- Enhance health education and outreach to the community
- Enhance referrals for specialty health care
- Enhance referral and outreach networks for mental health and substance abuse problems
- Develop local alcohol/drug treatment programs
- Utilize faith-based organizations more effectively
- Provide more public health and hygiene resources for homeless individuals, and
- Focus the Community Survey on health care access issues and the prevalence of major health problems in New Brunswick.

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Introduction

In March of 2001, New Brunswick Tomorrow initiated the Healthier New Brunswick 2010 campaign with the aim of developing and implementing a long-term strategy to improve the health status of residents of New Brunswick. The campaign has two components: engaging community leaders in developing and implementing community health interventions and conducting a systematic assessment of the health status and health care needs of the city's residents. The assessment's goals are to provide a baseline for measuring progress and insight into what interventions are needed and will be effective. The assessment began with a review of existing studies of health and health care in New Brunswick.

This report presents the results of the third stage of the assessment process – 12 focus group interviews in New Brunswick with 110 residents from different sectors of the community and with front line health and social service providers. These focus groups provided a grounded assessment of the health needs and health care issues facing the New Brunswick community. The focus groups also offered ideas for addressing these problems from diverse sectors of the community.

The next two sections of the report provide background information on the focus group study and a description of the study methods respectively. This is followed by a presentation of our findings. The report ends with recommendations based on the study findings.

Background

Health Needs in New Brunswick

New Brunswick, New Jersey—known as the Health Care City— is the seat of Middlesex County and home to Johnson & Johnson, Rutgers, The State University of New Jersey, the Robert Wood Johnson Medical School and two major teaching hospitals. New Brunswick continues to exhibit health and social problems that belie these resources.

Problems documented in previous studies of New Brunswick include poverty, unemployment, inadequate housing, high school drop-out rates, and insufficient access to quality health care. Residents of New Brunswick were reported in previous studies to be less likely than those in the state overall to have health insurance. The population continues to suffer a high rate of disease and death, as well as an abundance of dental, medical and mental health problems, and high rates of violence (Middlesex County Public Health Dept., 2001; Middlesex Public Health Dept., 2000; Eagleton Institute).

Role of the Assessment

Healthier New Brunswick 2010 is a collaborative process designed to meaningfully involve community-level stakeholders in the creation and implementation of measurable health improvements to be realized by the year 2010. The role of the needs assessment in the context of the larger Healthier New Brunswick 2010 initiative is to build on previous efforts by gathering detailed qualitative and quantitative information on health-related needs and resources in New Brunswick (including lessons learned from existing community activities), and engaging community members in the process of developing a systems approach to health improvement in response to these findings; this approach is presumed to include educational, preventive, and other broad-based interventions. Additionally, the intent of the assessment is to provide comprehensive information on the health and health care of New Brunswick residents that creates a baseline for monitoring progress in improving community health. Given the diverse population of the city, special attention will be paid in this effort to cultural knowledge, health behavior and traditional care seeking practices of populations at risk. These issues were of particular concern in the focus group interviews.

The specific goals of the assessment were:

- To engage community and health care leadership in developing avenues for health improvement and to ensure strong community ownership of this process and its results,
- To assemble qualitative and quantitative information about the health and health care of the residents of New Brunswick,
- To assess barriers to and assets for improving health, and
- To provide a resource for and educate policymakers, community leaders, providers and researchers.

Role of the Focus Group Interviews

The assessment has five stages: review of prior New Brunswick health care needs assessments, key informant interviews, focus groups, analysis of existing data available for small areas (e.g., hospital discharge abstract data, birth certificate data), and a community survey. The role of the focus group interviews is to develop an understanding of health problems and health care issues in New Brunswick from community perspectives and from front line providers. In contrast to the key informant interviews, those participating in the focus groups are not necessarily well known in the city. These are views from the "front lines" in many senses of the term.

The use of information gathered from this process is multi-fold. First, it provides a baseline of information against which future progress can be measured. Second, it provides the basis for the development of action plans to address the identified problem areas in the form of possible solutions. This includes identifying issues (such as the social determinants of health) that require collaboration and more broad-based problem solving or the application of other collective resources. Third, it raises issues and gaps in knowledge that can be addressed through other assessment mechanisms, in particular the community health survey. Overall, the focus group interviews are a vehicle by which information can be provided to those in key positions to address the state of health and health care delivery for residents of New Brunswick from those whose voices are less frequently heard.

Methods

Focus group participants came from a wide range of sectors of the New Brunswick community – clergy, elderly, teenagers, homeless individuals, Spanish-speaking residents, and community health care providers, such as school nurses. The goal was to represent front line providers of health care and social services and a diverse group of community residents. Suggestions of groups to invite to participate came from the members of the Data Advisory Group (DAG), a sub-committee of the New Brunswick Tomorrow Community Health Advisory Group. As with the key informant process, the DAG was asked to identify groups within the community that represented the different points of view of community members in New Brunswick. After narrowing down the original list of possible groups to include in the study suggested by the DAG, we strived to obtain a diverse sample of community members with varied backgrounds and perspectives (see Appendix A for final list). A total of 12 focus groups were conducted, with 110 participants overall. Forty-six percent of the participants

lived in New Brunswick and 57% worked in New Brunswick. Sixty-eight percent of the participants were female. The sample was diverse in terms of ethnicity: 46% were Latino, 30% European American and 16% African American. Fifty-nine percent of the participants were born in the United States. Sixty-two percent of the participants spoke English as their primary language and 34% spoke Spanish. These ethnic characteristics of the sample for the focus groups reflected the goal of understanding the health care needs and experiences of the growing and changing Latino community in New Brunswick.

Focus groups were carried out between May 2002 and May 2003. For each group, two members of the assessment team were present, one to lead the focus group and one to take notes during the session. All of the focus groups were tape-recorded to allow the assessment team to clarify any unclear notes. Most of the focus groups lasted from one and a half to two hours.

The focus groups were semi-structured, although there was a guide of specific questions that we wanted all focus groups to address. The focus group leader from the assessment team had the flexibility to follow interesting lines of inquiry or to modify questions as he saw fit. At the beginning of each focus group, participants were asked about their experiences with the healthcare system in New Brunswick and at the end they were asked to suggest additional areas for improvement. The main questions in the interview guide were the participants' views on the following:

1. What do you see as the major health problems in New Brunswick today?
2. What do you see as the major strengths/resources in New Brunswick relative to health and health care?
3. How would you describe the overall status of health and health care in New Brunswick? What grade would you give the city?
4. What health-related resources do you think the city has that are not being used to their full potential? What health resources could be used differently to improve health and health care?
5. What kinds of things do you think could be done or programs developed to improve health and health care in New Brunswick? We're interested in initiatives that could be taken by all sorts of players: local health care providers, non-profit organizations, schools, faith-based institutions, Rutgers, industry, local government, state government.

The following questions were only asked of the community resident focus groups:

1. Have you ever tried to obtain health care in New Brunswick? What has that experience been like for you? [Probe for medical health, dental health, behavioral health. Ask about both negative and positive experiences and reasons for both.]
2. Do you have health needs that you haven't tried to get help for or that aren't being met? Why not?

These questions were designed to be parallel to the questions used with the previous key informant interviews.

Members of the assessment team created a written summary of key points following each focus group. The lists from the different groups were reviewed to generate a composite list of key points raised by the community participants.

Findings

The key issue that emerged in the focus groups was access to health care. Participants identified a wide range of access issues and made it clear that access is a complex problem in New Brunswick. While many of the standard access issues such as lack of insurance and transportation problems emerged in the discussions, there were a wide range of access problems that do not usually surface in discussions of access to health care. We will detail these issues in the next section.

Access to Health Care

Insurance issues loomed large for residents of New Brunswick. There is a large group of residents who do not have health insurance at all. These include undocumented immigrants, homeless individuals and working poor families. Many residents had public insurance, but found that their access to health care resources was severely limited by who took their insurance. Another issue that emerged was that as public insurance moved participants to managed care programs, they had difficulties navigating the system. They could no longer use services as they had under the Medicaid fee-for-service program. In particular, participants reported that Medicaid patients' access to emergency rooms was curtailed.

A related issue, not often heard, is how the changing insurance climate affected the reception of community residents in the health care system. Even those with insurance felt declining respect from their health care providers. When they came for health care, instead of

being asked how they were and what their problem was, the first question they were asked was did they have insurance and what kind. More broadly, they found their plans were rigid and forced longer waits between appointments.

In spite of New Brunswick's relatively small size, people cited transportation as a significant problem. Many low-income residents did not have their own cars. Public transportation is extremely limited and does not go from where the majority of residents live to health care facilities. Transportation services are relatively limited to the Route 27 corridor which is not convenient to the two major community facilities that residents attend: the Chandler Clinic and the St. John's Clinic. When people needed specialty services, they were often located outside New Brunswick, creating even more difficult transportation problems.

Another significant access issue was the severe over-crowding of community services such as the Chandler Health Center and St. John's Clinic. Most of the focus groups described these two facilities as the health care life lines for the community. These facilities were often the only places people could go with the insurance or self-pay options they had. This meant that these facilities were often over-crowded. Both community residents and community providers commented on the difficulties in getting appointments because of the heavy use of these services and the intense dependence of the community on these two facilities.

For the growing Latino community in New Brunswick language issues were significant barriers to gaining access to health care. Another reason that Chandler and St. John's were so over-crowded was that they were the only facilities identified that consistently had bilingual/bicultural staff. In both provider and community resident groups, particularly with newly arrived Latino immigrants, communication issues loomed large. Latino residents were often reluctant to even seek health care if they did not feel they could find someone who spoke their language. Chandler and St. John's not only had interpreters, but also had bilingual providers. While Spanish was not the only language identified, it was overwhelmingly the predominant one.

A second impact of language in receiving quality care was receiving and understanding appropriate instructions about treatment and medications. In one group, a participant noted that all of the prescriptions were written in English. A Spanish monolingual woman took 11 pills a day instead of one because the only word she could make out in the instructions was "once" – which in Spanish would be the number 11 instead of its meaning in English of one time per day. Provider groups in particular were very concerned that they often did not know the full implications of these kinds of communication barriers in health care.

A related issue is the problem of gaining access to care for people who do not have legal documentation. While this was a particularly large problem in the Latino community, it affected other immigrant groups such as those from the West Indies. People were often afraid to access care even when they were in serious need because of fear of being identified to immigration authorities. Immigrants were not aware of their rights to health care under specific circumstances such as being in labor and delivering a baby.

Another significant barrier to access was knowledge of where to go for care. One aspect of knowledge was how to navigate the health care system. Many focus group participants noted that there was no one place to go to get all their health care needs met. Another was knowing what services were offered and how to gain access to them. Many residents did not know that charity care was available and how to request it. This prevented people from getting needed care if they did not know how to pay for it. Providers discussed how complicated gaining access to charity care is since residents first have to apply for and be denied Medicaid before they could then apply for charity care.

Hours of operation were another access issue. Groups noted that having only day time hours prevented people who worked from getting care. More evening and weekend hours were needed.

A final aspect of access issues was the stigmatized nature of certain kinds of services. Stigma was particularly marked for mental health, substance abuse and sexually transmitted infections services. Also, some groups of people felt stigmatized when they tried to use health services. In particular, this issue was raised by people who were homeless and those with disabilities.

Major Health Problems

We will present the major health problems in a developmental perspective, starting with those of young children, then adolescents, followed by adults and senior citizens.

The most frequently mentioned problem among school age children was oral health. School nurses in particular noted the severe dental health problems of school age children. These problems emerged from a combination of lack of accessible dental care, diets that fostered tooth decay and lack of fluoridation of New Brunswick's water supply. Dental problems had wide-ranging consequences for children. As their teeth deteriorated, they could not eat well, leading to low energy and inability to concentrate in school. Their deteriorating teeth also affected their self-esteem because they affected the way they looked and smiled. Even when families had some kind of health insurance, they often did not have dental coverage. While dental services had been offered in schools at some times, they were

dependent on grants which were not always available, making care often inconsistent. Children and families lacked education about dental hygiene and the effects of sugary snacks and soft drinks on dental health. Even when children got dental care, families did not have the funds to pay for follow-up medications such as antibiotics for infections and fluoride treatments. When families gathered their resources for one child, they sometimes split it among several children since dental problems are widespread.

Other widespread problems among children included asthma, obesity, and hyperactivity. A related problem to obesity was rise in blood pressure and glucose levels, signaling the development of hypertension and diabetes in later years. A further problem related to the access issues discussed above is that children do not receive complete immunizations at the appropriate times.

Both providers and adolescents identified alcohol, drugs, and sexually transmitted infections as important health problems affecting this age group. Additional issues were cigarette smoking and teenage pregnancy. Teens identified the dual problems of lack of money and stigma as barriers to getting help with these problems.

The major adult health problems in New Brunswick were diabetes and hypertension. Many groups identified these problems as epidemic in the community. Many of the community participants discussed their own experiences with these health conditions. In addition to all the barriers to care mentioned earlier, a major issue that emerged in discussions of diabetes and hypertension were the difficulties in gaining access to specialty care for these conditions. Lack of knowledge was also a significant factor in diabetes and hypertension. Residents did not often recognize the connection between dietary factors and these conditions. Dietary issues were heightened for those going through a transition from living in rural areas where people ate food that they produced to coming to an urban area where foods were purchased in highly processed forms. People also noted a decrease in activity levels here as contributing to these health problems.

Mental health issues, specifically depression, were other major adult health problems. One source of depression was the change related to immigration and loss of supportive social networks. Depression among women was often associated with a cluster of problems that included alcohol abuse in men and domestic violence. Alcohol abuse was further related to the stresses of working long hours, multiple jobs, low pay, and obligations to support family members in the home country.

Domestic violence was another significant health problem. Residents had a complex understanding of the sources and treatment of domestic violence. For some women, leaving

their male partners was not a clear option. This was especially true for immigrant and undocumented women. While shelter provided an important refuge and respite from the abuse, women often needed longer term solutions which were not available to them. They often could not get jobs that paid enough even for child care, leaving them without resources for food, shelter, clothing and other necessities.

Among the elderly, the key health problems were also diabetes, depression and hypertension. Depression was a significant concern for isolated elderly, even those living in senior apartment buildings. Many of the elderly were now experiencing the health consequences of their diabetes and hypertension, including eye and foot problems, and more severe disabilities.

Summary of Findings

Focus groups with a broad spectrum of community residents and front-line health care providers in New Brunswick identified serious health problems and a stressed health care deliver system. The key issues they addressed revolved around access to health care for many segments of the community. Dental problems in children were a major source of concern. Additional childhood concerns revolved around dietary behaviors and obesity. Adult problems focused on chronic diseases and the problem of obtaining referrals to appropriate specialty care to cope with these problems. Many unmet needs in the areas of mental health and substance abuse problems were also addressed. Several of the groups also identified problems of language access to services and the lack of more culturally competent providers in the broader health care system.

The focus groups also revealed some important strengths in New Brunswick's health care system. Participants were particularly appreciative of the care they received in the primary health care centers in the community and of the efforts of staff there to assist them with a broad range of health and social problems. They also appreciated the efforts these centers made to reach out to the growing Latino community. School nurses were extremely knowledgeable about the health problems facing school age youth and willing to extend themselves to attempt to meet those needs. The faith-based community, which has extensive contact with many segments of the New Brunswick community, was very interested in providing more information to the community if they received appropriate training on health issues and health resources in New Brunswick.

Recommendations

Based on the focus group interviews, we developed a set of recommendations. In some cases, these recommendations represent respondent suggestions, or elaborations of respondent suggestions. In other cases, they represent the study team's thoughts on possible responses to the problems identified by the respondents. While the focus groups included individuals with a broad spectrum of perspectives, it is important to bear in mind that these recommendations arise from conversations with a limited number of volunteer group participants. Future research, using data sources more broadly representative of area residents will add important additional information for drawing recommendations for improving health and health care in New Brunswick.

- *Expand Community-Based Primary Health Care Services*
  One of the major needs identified by the focus groups was to develop more or expanded primary care centers like the Chandler Health Center to serve the various neighborhoods in New Brunswick. Providers and residents all saw the value of the more comprehensive approach to health problems provided by Chandler. They also valued the sensitivity of Chandler to community needs and concerns, including more bilingual/bicultural staff and social work assistance in obtaining referrals to other health care and dealing with a range of social problems. Centers like Chandler are also valued because they accept a wide range of public and private insurance and have flexible fee structures to assist people who need to pay for their own care.

- *Improve the cultural competence and language capacities of health care programs and providers*
  Given the ever-changing ethnic and cultural make-up of New Brunswick residents, there is a strong need to emphasize cultural competence among health care and social service providers. This need exists in all of New Brunswick's health care and social service programs and agencies. There should be an increased effort to hire more bilingual/bicultural professionals and support staff. While the most pressing need is for those who speak Spanish to serve the rapidly growing Latino community; there are also needs for other languages such as Haitian Creole.

- *Expand school based health resources*

  Schools have the potential to provide screening and preventive services to a wide range of children who might not otherwise get health care. For primary school children, there is a pressing need for dental services. This includes not only preventive care, but referrals for restorative care as well. A related area is education on healthier eating both to prevent dental problems and to deal with the increasing problem of obesity and its related health effects. For adolescents, expansion of programs to help students deal with sexuality, substance abuse (including cigarette smoking) and family conflict are particularly needed. Schools can serve as a site for early detection of health and mental health problems; a key problem is connecting students to more comprehensive services to help them cope with those problems.

- *Enhance health education and outreach to community residents*

  The focus groups identified a number of areas where community residents needed more information on health and mental health issues. One area of need is information on how to navigate the health care system, particularly in terms of effectively obtaining and using referrals to specialty care for problems such as hypertension, heart disease and diabetes. A related issue is better community information on what resources are available and how to access them, such as expanding and promoting the New Brunswick info-line and making it more accessible to those who are limited English speakers. Another area is the importance and timing of various kinds of screening and preventive interventions such as vaccinations, cancer screening and dental check-ups. Recent immigrants need information on their rights to health care and how legal status may affect health care access. Participants also identified information on child rearing as a need both in terms of more effective parenting and dealing with the changes in parent-child relationships due to acculturation processes.

- *Enhance referrals for specialty health care*

  Once primary care centers identify serious health problems such as cancer, diabetes or hypertension, they need to be able to refer people on to specialty services. Both providers and community residents noted serious problems in gaining access to specialty care, particularly for patients with public insurance or who were uninsured. One recommendation is to provide more information on which specialty providers are

available to see low income and uninsured patients. A second recommendation is to strongly encourage specialty care centers to provide more care to those with public insurance or to those who lack insurance and might pay on a sliding fee scale.

- *Enhance referral and outreach networks for mental health and substance abuse problems*

  Mental health problems, particularly depression, were frequently mentioned in the focus groups. Public education campaigns to reduce the stigma of seeking and using mental health services are needed. These should be tailored to address the particular concerns of different ethnic communities. Since mental health and substance abuse programs are often separate from health programs, clearer information on what services are available and how to link to them are needed for both health care providers and community residents.

- *Develop local alcohol/drug treatment programs*

  Focus groups identified a severe lack of substance abuse treatment programs in New Brunswick. These kinds of programs need to be developed in New Brunswick where the need is significant. There is also a need to strengthen linkages between alcohol and drug use treatment programs as people often suffer from both problems and to provide services once people leave inpatient treatment programs, such as drop-in centers, to help prevent relapse. Focus groups identified a need for programs in Spanish, both treatment and family support programs (such as Al-Anon).

- *Utilize faith-based organizations more effectively*

  Local faith-based organizations are an untapped resource for information and referral from the community into the health care system. There is a growing network of clergy who are meeting to provide these services through pastoral services and community development corporations. There is a need to provide more training to faith based organizations on the services available in the city and how to advocate for community residents to effectively gain access to services. Health and social service agencies also need training in the value of collaborating with faith-based organizations.

- *Provide more public health and hygiene resources for homeless individuals*
  Homeless individuals identified the lack of accessible toilets and showers as a barrier to healthier lives. Public institutions in New Brunswick should develop facilties to make these resources more available to homeless individuals.

- *Focus the Community Survey on health care access issues and the prevalence of major health problems in New Brunswick*
  The Community Survey provides an opportunity to assess health care access issues and major health problems in a systematic fashion across all segments of the community. The Community Survey should include detailed questions to identify the specific kinds of access issues faced by community residents; these areas include insurance issues, transportation barriers, language problems, and lack of respect or receptivity on the part of providers to certain segments of the community. The survey should document the extent of major health problems, including specific diseases and health related behaviors that underlie them. The list of health problems should focus on those identified by both the key informant interviews and the focus groups.

Appendix A

FOCUS GROUP CATEGORIES

Senior Citizens

School Nurses

Clergy

Homeless Men

Spanish-speaking medical interpreters

Faith-based community development corporations

High school students

Spanish-speaking health care consumers

Victims of domestic violence

HIP HOP medical student group

Social service outreach workers

Mental health and substance abuse coalition members

Appendix B

FOCUS GROUP INTERVIEW GUIDE

Introduction:

Today we are going to be talking about health and health care in New Brunswick. We are involved in a long term project to improve the health of residents of New Brunswick. To help us develop this project, we want to better understand the needs of the community from people in the community. We will be having group discussions like this with various groups of people in the city to get a wide range of ideas and opinions from different groups.

Specific Questions:

1. What do you see as the major health problems in New Brunswick today?

2. What do you see as the major strengths/resources in New Brunswick relative to health and health care?

3. How would you describe the overall status of health and health care in New Brunswick? What grade would you give the city?

4. What health-related resources do you think the city has that are not being used to their full potential? What health resources could be used differently to improve health and health care?

5. What kinds of things do you think could be done or programs developed to improve health and health care in New Brunswick? We're interested in initiatives that could be taken by all sorts of players: local health care providers, non-profit organizations, schools, faith-based institutions, Rutgers, industry, local government, state government.

6. [Only ask these questions of community residents]

7. Have you ever tried to obtain health care in New Brunswick? What has that experience been like for you? [Probe for medical health, dental health, behavioral health. Ask about both negative and positive experiences and reasons for both.]

8. Do you have health needs that you haven't tried to get help for or that aren't being met? Why not?