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PRACTICE-BASED ARTICLE

## Engaging a community for youth mental health and wellness: Reflections and lessons learned

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### Abstract

As clinicians at a university-affiliated health centre faced with youth mental health and substance use concerns, we reached out to the local community for guidance. We partnered with community leaders to explore how to best understand the issues and engage with the community. Using a community-engaged research (CEnR) approach, we conducted a needs assessment to explore the issues and inform change. We formalised a partnership with the local school and community board, which led to the creation of a Community Alliance. Our engagement efforts allowed us to understand the community more deeply and establish more effective change. Our most successful outcome was the development of a youth mental health and wellness Action Plan which helped direct our strategies moving forward. This article highlights our community engagement activities, processes and lessons learned, which may be of benefit to other academic researchers and clinicians who are interested in CEnR.

### Keywords

community engagement, community-engaged research, family medicine, youth wellness, mental health, youth

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## Introduction

As clinicians working in a university-affiliated community health centre in a small urban community in Canada, we encountered increasing rates of undiagnosed mental illness and substance use disorders in our youth. This was concerning to us, so our health team met to discuss an approach to address these issues and decided that, in order to be effective, we would need to involve the wider community in the development of appropriate strategies (Glandon et al. 2017).

We were aware of a strong leadership group within the community, so we approached them with the idea of creating a partnership to develop solutions for better supporting these young people using a community-engaged research (CEnR) approach. CEnR values engagement with the community as partners and stakeholders (Ballard & Syme 2016; Blachman-Demner, Wiley & Chambers 2017), ranging from minimal engagement to full participation or collaboration, such as in community-based participatory research (CBPR) (Blachman-Demner, Wiley & Chambers 2017; Goodman et al. 2017; Israel et al. 1998; Shea et al. 2017; Vaughn et al. 2017).

In keeping with the principles of CEnR, we attempted to understand the history and structure of the community in order to effectively engage with them (ATSDR 2019; Balls-Berry & Acosta-Perez 2017). The community is located on the outskirts of the main urban city and has a distinct sense of identity. It traces its roots back to the early 1930s when residents of the larger city moved there to escape the burden of city taxes. A strong sense of unity has been evident over 80 years of the community's existence. Community members support each other during times of hardship, for example, by rebuilding a home after a fire, or holding a large fundraising event for a family with an ill loved one.

As depicted in Figure 1, the impetus for an inductive approach arose from a clinical concern. This in turn led us to collaboratively reflect on an approach to the issue within the community, resulting in a strategy to help support youth wellness. The purpose of this article is to describe how we, as clinicians and researchers, engaged with a community to evaluate and promote youth mental health and wellness. We also describe our research and engagement process and our challenges and lessons learned, which may be of benefit to academic researchers and clinicians who are interested in CEnR.



Figure 1 Community Engaged Approach

## Foundational Work

### COMMUNITY CONSULTATION

One of the unique features of this community is that it has always had leadership from within. This leadership has been expressed primarily through the local community board. The board started as a neighbourhood improvement association and is made up of community members, advisers from the local school, health centre and larger community, and representation from the city council. The mandate of the community board is to ensure that the strong value of community is promoted through various initiatives.

The initial meeting between the health centre and the community was comprised of three leaders from the community board and representatives from the health centre, including two nurses, one social worker, one pharmacist, two receptionists and four family doctors. It was decided at this meeting to plan a community information night, the purpose of which was to discuss substance use in general and to elicit strengths and concerns from the community specifically.

To advertise the event, brochures were distributed and a large sign was placed at the start of the road leading to the community. With guidance from community leaders, the sign read *'Let's talk about drugs'* and depicted an injection needle. Within hours of the sign being erected, significant negative feedback had been posted on the community Facebook page as some in the community felt it was stigmatising the community. Some of those objecting to the sign promptly removed it and laid it carefully on its side without damaging it. The team was apprehensive about continuing with this initiative, given this swift and robust demonstration by certain members of the community. The community leaders viewed these actions as an indication of both interest and the need to protect the privacy and reputation of the community, and urged the meeting to go ahead as planned with less provocative advertising. The event was subsequently announced by means of household flyers.

Given the initial controversy and the importance of the topic, the community information night was well attended and there was much frank discussion. The discussion confirmed the presence of drug use in the community, and those present speculated that it was no better or worse than other areas of the city or province. The group expressed a desire to find ways to prevent drug use problems and invited the organising members to lead in planning a strategy. With a commitment of support from the community, the planning group resolved to move ahead to further assess the situation and address the resultant needs.

Reflection on the initial community gathering confirmed a need for greater effort by us, as clinician researchers, to further strengthen our partnership with the community. Determining the community's needs and establishing a strategy for a needs assessment were recognised as important aspects of this community engagement (Adams et al. 2017; Brunton et al. 2017; Cutforth & Belansky 2015).

### TEAM PREPARATION

Our research team consists of members who cross disciplines, backgrounds and lived experiences, and range from novice to more experienced researchers. When we initially came together, we had only a rudimentary understanding of community-based research methods. As we began reading the literature and planning for our needs assessment, we realised that we wished to align our approach more closely with the principles of CBPR (Israel et al. 1998) and

that some further education and familiarisation with both CBPR and CEnR would be helpful moving forward (Dubois et al. 2011; Hardy et al. 2016; Matthews et al. 2018; Shea et al. 2017). It was from this point that we made a conscious effort to become more familiar with the principles of CBPR to prepare the team for community research. We reviewed background materials and articles, attended conferences and presentations, and held many discussions with community leaders and members. In addition, we consulted experienced researchers with expertise in the area of CBPR (Matthews et al. 2018).

Through our collaboration with the community board, they suggested that the research initiatives be presented to the community as a partnership, and not as solely university-based research. Thus the Community Alliance was officially formed, comprising the clinicians at the health centre, the local school administration and the community centre board. The Alliance's mandate was to explore and suggest actions to improve youth mental health and wellness in the community. This Alliance has come to be the main collaborative group promoting youth mental health and wellness through a variety of strategies, including research, education, engagement and programming (Figure 2).



Figure 2 The Community Alliance

## NEEDS ASSESSMENT

The community was involved in the planning, design and delivery of the needs assessment, which is rooted in the idea that research involves meaningful involvement and sharing of power (Arnstein 1969; Yonas et al. 2013). In order to maintain this balance of power, all members of the team must have equal input, so it is crucial that appropriate levels of communication are maintained (Jones & Wells 2007).

Initially we made great efforts to implement CBPR, assuming an iterative approach when responding to the community's needs. We felt that we were conducting CBPR to the best of our ability during the needs assessment. The community was receptive to our research efforts and supported aspects of CBPR. Eventually, however, we recognised that our approach was more consistent with CEnR and in subsequent projects we were able to be more explicit about our methodology (Goodman et al. 2017; Vaughn et al. 2017).

One of the first steps of our Alliance was to agree upon the approach for conducting research. It was agreed that all research initiatives, community presentations and materials for documentation, publication or distribution (such as newsletters, pamphlets, posters) would be vetted by the community as represented by the members of the community board. We offered to collaboratively develop a written research agreement as is frequently done in community-

based research (Yonas et al. 2013). However, the board did not see a need for a formalised agreement and was comfortable proceeding through ongoing dialogue. A community board member became a part of the research team, attended research meetings and contributed to the research. In addition, the Alliance became a standing item on the agenda of board meetings, which were held every two weeks. This ensured that both new and existing initiatives would be vetted by community representatives. By incorporating the research process into the life of the community through its board, the Alliance has served to bridge the gap between the university affiliated researchers and members of the community. It has also enabled the research to stay more grounded in the issues that face the community's youth.

With this structure in place to ensure participation by the community, the Alliance formulated its research plan in the summer and autumn of 2012. We agreed that we would receive ethics approval for all research. An accurate picture of the current drug use and mental health status of the youth and young adults aged 12–34 was the initial goal. We decided to review the charts of all of the youth and young adults who attended the health centre to determine the prescribing patterns of the physicians at the health centre and the risk factors for substance misuse. This was determined by the use of a standardised risk calculator, the Opioid Risk Tool (Webster & Webster 2005). The audit revealed a low rate of prescribing of opioids and stimulants, but also indicated that a relatively small proportion of youth attended the health centre. This was a concern as we recognised that there may be youth within the community who could benefit from the services that we provide.

Our other goal was to form a better understanding of the current substance use and mental health status of the youth and young adults in our community. We felt this was best achieved through surveying the community, using a well-validated survey tool (Dep-ADO 2007). Despite much effort on behalf of the Alliance to promote the survey in both paper and electronic formats and by offering a prize, not many surveys were returned. Although the responses did not indicate that substance use and mental health concerns were prevalent, the results were not felt to be representative of the population given the poor response rate. The survey results captured a high proportion of the junior high school cohort, which was largely due to the support of the principal, who was a member of the Alliance.

Based on feedback from the initial public community meeting, it was suggested that hearing the perspectives from all community members would be beneficial (Dresser 2017). The Alliance decided on a qualitative approach to obtaining further information from the community at large (Fossey et al. 2002). Our goal was to gather their perspectives on the status of substance use, the barriers that prevent addressing mental health and substance use concerns, and the strategies that could help. We initially offered focus groups to adult community members and professionals working in the community (e.g. medical staff, teachers, clergy). Including professionals in the research was suggested by community members as they felt they would provide a unique insight. Due to low interest from community members in participating in focus groups, likely due to the lack of anonymity, we subsequently offered the option of individual interviews. In addition, it was suggested that speaking directly to the youth would be informative, and a focus group was held with youth from the community. We sought the expertise of the university's primary healthcare research unit in helping conduct the focus groups and interviews.

From the needs assessment, a number of themes emerged around the issues of youth mental health and access to services. The themes fell into four categories: (1) geography of the community; (2) community attitudes and perceptions; (3) mental health and substance use services; and (4) prevention approaches. The themes were collated and presented to the

community for discussion and direction. Presentations were given to the community board, the local school council of teachers and parents, students, and the community at large. At each venue the Alliance sought feedback and direction, which was translated into an 'Action Plan' for youth mental health and wellness in the community. This plan, which is described more fully below, helped to shape future initiatives (Cutforth & Belanksy 2015; Lamb et al. 2014).

## COMMUNITY ENGAGEMENT

Initially, our Alliance was more focused on delivering education and conducting research. This was challenging as only a small number of community members were attending events or participating in the research. In an effort to keep the agenda at the forefront of the community, we organised several education activities centred around youth wellness and mental health. These too attracted limited attendance, causing us concern in the early stages of the project.

As a result of these participation challenges, and through consultation with experts in the field of community engagement, we made a conscious effort to engage with the broader community in order to further develop trust and relationships (Pullmann et al. 2013; Stein & Mankowski 2004). We began by attending and participating in a number of community events, such as folk festivals, community vigils and winter festivals, which not only increased our visibility (Matthews et al. 2008; Michener et al. 2012), but also gave us a sense of belonging and greater understanding. This engagement cemented the relationship between the researchers and the community, provided a venue for feedback, and strengthened mutual understanding and trust. In turn, this has translated into more community participation and support for initiatives undertaken by the Alliance. Figure 3 outlines our community engagement efforts.

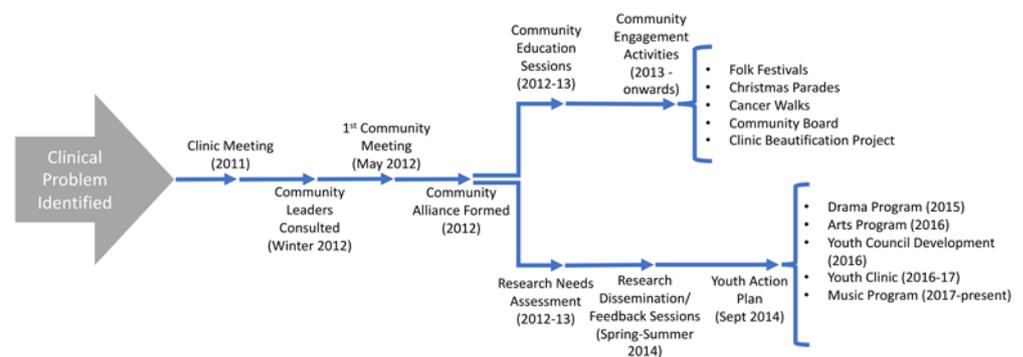


Figure 3 Engagement Process Arms

During our engagement efforts, we noted that the community felt stigmatised by the constant reference to mental illness and addiction. They suggested using a more positive focus, and we started referring instead to 'mental health and wellness'. This change addressed the sensitivities of the community and prompted a more strengths-based approach. The shift in language also effected improved willingness in community members to become involved with our research.

After our research team completed the needs assessment, the findings were collated and presented for discussion in a number of public forums: (1) the community board; (2) the local school council of teachers and parents/students; and (3) the community at large. When planning the community event, we directly involved select community members. Based on their suggestions, we invited two prominent members of the local artistic entertainment circle with lived experience of mental health issues to attend and speak about their struggles

with mental health. The Alliance presented the main findings from the needs assessment and facilitated discussion in small groups. We then compiled the feedback from all of the public forums and formulated a Community Action Plan for the promotion of youth mental health and wellness in the community. The draft Action Plan was subsequently presented to the community board for their comment and approval (Lamb et al. 2014).

## COMMUNITY ACTION PLAN

The mission of the Action Plan was to promote prevention, early detection, and appropriate treatment of mental illness and substance use in youth and young adults, and thereby promote their mental health and well-being. The Action Plan used a strengths-based approach and was designed to be inclusive, accessible, practical and outcomes-oriented. It has become our guiding document as it directly addresses methods to actively engage youth and support their mental health and wellness. The Action Plan centres around three main themes: (1) improving access to mental health services; (2) keeping youth healthy and happy; and (3) capacity building within the community. The plan is broken down into objectives and strategies for achieving these themes (Appendix 1).

Much of our efforts to implement the strategies of the Action Plan have centred around identifying meaningful ways to engage with youth in order to help support their health and well-being (Dunne et al. 2017). One challenge has been identifying funding sources to support the initiatives as each funder has their own agenda, which requires careful navigation to preserve the direction of the Action Plan.

One of the initiatives under the new Action Plan was using drama and the arts to engage with youth. A drama project for the junior high students was the result of a great deal of collaboration on the part of the school and the Alliance, and outside professional directing. The production of *Romeo and Juliet* involved a number of the youth and the performance attracted many parents, relatives and neighbours to the event. The following year, an arts program focused on the visual arts was offered. This program expanded the interface between arts and mental health more explicitly by including mental health education. The program ended with an exhibition open to the community, and many of the student artworks are on permanent display in our local health centre. Both of these initiatives were positively evaluated by the young people who participated. Unfortunately, funding limitations prevented us from continuing with these initiatives.

Concurrently with these initiatives, a youth council was formed. The council planned and executed events, such as a community clean-up, and provided ideas for future wellness projects. While this proved to be a great way to engage with youth, it required investment of time and human resources. The research assistant who was mainly involved in coordinating the council spent considerable time connecting with youth, checking in via text and social media, and helping to organise and facilitate meetings. Since she was closer in age to the youth, she was able to establish some meaningful connections with them. However, while it was successful, it was eventually shifted to an existing community youth drop-in group to ensure its sustainability.

Our most recent initiative was securing a community-based, not-for-profit music program for the school-aged children of our community. This program offers free community-based string lessons to children residing in areas that have few opportunities for music education, with the intent that they will positively benefit growth and learning. Part of the success of this initiative is that it is an established program in another area of the city and they had

the capacity to expand into our community. This program is run by a board of directors that obtains independent funding, enabling it to be sustainable. The program has now been running for three successful years in our community.

## EVALUATION AND KNOWLEDGE TRANSLATION

An evaluation was incorporated into all of our projects, using both quantitative and qualitative approaches. This helped us determine the benefits and challenges of delivering these projects. The needs assessment helped inform the development of the Action Plan and the evaluation of specific projects helped provide guidance on the future direction of the Alliance.

The Alliance placed an emphasis on knowledge translation efforts, in both community and academic forums, and with the media. Community members have jointly presented with us at local events and academic conferences. Their participation has provided a unique perspective and has resulted in richer discussion with the audience members (Shea et al. 2017). Print and radio media coverage has been useful in connecting with more people in less ‘academic’ settings (Blachman-Demner, Wiley & Chambers 2017; Michener et al. 2012). For example, representatives of the Alliance, a community member and two clinicians, presented at a national community-university partnerships conference. Following the presentation, the media interviewed the community member, which resulted in an article in the local newspaper.

Throughout this process of design, study and engagement, we, as a team of researchers and clinicians, have participated in many reflexive discussions. We have reflected on the principles of CBPR and CEnR, decisions on representation of voices from the community, and our roles as researchers (Elliott, Fischer & Rennie 1999; Fassinger 2005; Stein & Mankowski 2004). We have attempted to embrace a collaborative approach in all that we do, up to and including the writing process, using a web-based tool for real-time writing and editing, and a dropbox for access to documents and articles (Flicker & Nixon 2018).

## Discussion: Outcomes and Lessons Learned

This long-term CEnR and youth wellness initiative has resulted in successes, challenges and learning opportunities. CEnR, which utilises community and academic partnerships, requires the building of capacity, leadership (Hardy et al. 2016) and trust over time (Balls-Berry & Acosta-Perez 2017) to be effective in addressing health issues (Goodman et al. 2017) and empowering community members involved in the research (Khodyakov, Mikesell & Bromley 2017). Being responsive to the community needs throughout the project has allowed us to modify our approach and better support the youth (Figure 1).

Throughout this process, we have come to learn some valuable lessons about community engagement and conducting health research. We hope that other researchers interested in conducting CEnR can learn from our lessons outlined below.

*Take guidance from both experts and the literature.* Reaching out to experts in the field of CBPR and consulting the literature was extremely beneficial in helping guide our approach and research methodology. However, as we progressed throughout the project, we recognised that more formal training earlier in the process would have been advantageous (Coffey et al. 2017; Dresser 2017; Dubois et al. 2011; Matthews et al. 2018; Shea et al. 2017).

*CBPR is a demanding methodology.* Our research team embraced and used many of the principles of CBPR (Israel et al. 1998). However, similarly to McElfish et al. (2019), we were not able to fully implement CBPR principles for many reasons, including the significant

investment needed in terms of time, effort, training and resources. We realised that a shift towards CEnR was more realistic and had more potential for successful outcomes (Dubois et al. 2011).

*CEnR is a valuable research approach.* As clinicians, we recognised that collaborating with our community would be much more effective than working alone. Our goal from the beginning was not only to explore the issues, but also to use the research and partnership with the community to inform change. We learned it was important to be flexible and iterative in the process and to negotiate priorities along the way. Using the CEnR approach (Shea et al. 2017), we gained a deeper appreciation of the issues facing the community, which contributed to a more accurate interpretation of the findings.

*Formalise the partnership.* It is important to reach out to local community groups to determine who the leaders are within the community and engage with them to identify the key stakeholders. Establishing the Alliance was one of our main successes as this helped solidify our partnership and gave us standing on the community board. By incorporating the research process into the life of the community through the community board, the Alliance served to bridge the gap between the academically affiliated researchers and members of the community. Others have noted strength in overseeing projects through a community advisory board (Holzer, Ellis & Merritt 2014; Wine et al. 2019), which shares similarities with our model.

*Share the vision.* It is essential that all partners believe in the overall purpose of doing research. We surrounded ourselves with people who had similar goals. The formation of the Alliance gave us the opportunity to establish a shared vision early in the process.

*Listen deeply and be trustworthy.* We aimed to consider the community's goals above our own scholarly agendas. By being transparent and collaborative, the research team built the groundwork for mutual trust (Khodyakov, Mikesell & Bromley 2017). Through active listening and responding to the wishes of the community, we were able to adjust our approach, resulting in more valuable research.

*Maintain the engagement and keep a visible presence.* Similarly to other CEnR endeavours (Cutforth & Belanksy 2015; Redman et al. 2017), we initially attempted to engage with community members through our consultations, a needs assessment and connections with board members. However, we recognised that there were times when we could have drawn upon the wisdom of more grassroots community members (Dresser 2017; Matthews et al. 2018). We have come to recognise that engagement is important for its own sake.

*Invest in youth.* Our approach would have been strengthened by recruiting youth to become prominent members of the research team (Jacquez, Vaughn & Wagner 2013), including training them to conduct focus groups (Pullmann et al. 2013; Ramanadhan et al. 2016). A stronger presence of youth in the research process may have increased the success and outcomes of our projects (Dunne et al. 2017; Garinger et al. 2016; LoIacono Merves et al. 2015).

*Disseminate the findings.* We attempted to engage in different forms of knowledge translation, including presentations, news articles, community forums, manuscripts and social media (Blachman-Demner, Wiley & Chambers 2017; Michener et al. 2012). We found it useful to involve community members throughout the dissemination process as this helped validate the research and also served as a way to inform more community members of the findings. This was not without challenges, such as time constraints, lack of interest in writing and changes in membership of the community board.

*Maintain the momentum.* Our research involved long periods of behind-the-scenes activity, during which it was hard to maintain visibility and momentum. Participating in community events enabled us to sustain an active presence, kept us interested in the process and reminded us about the importance of our shared vision.

*Achieve practical outcomes.* The development of the Action Plan for youth mental health and wellness was our most successful outcome (Appendix 1). It was the result of a consultative process that reflected the needs of the community and helped direct our strategies moving forward. Our engagement efforts ensured a richer interpretation of the results and allowed us to operationalise our Action Plan more effectively. In keeping with the principles of CENR (Shea et al. 2017), regular review of the Action Plan is needed in order to determine how well we are achieving our goals and to reaffirm that the strategies are still relevant.

## Conclusion

Meaningful engagement with a community is realised through long-term partnerships and relationships built on trust. Our experience, as clinicians in a university-affiliated community health centre, has taught us the importance of participating in the life of the community outside the confines of our offices. We have also come to increasingly value the voices and expertise of the community members as we work together to promote youth mental health and wellness. Effective engagement involves active listening, a visible presence, flexibility and collaborative processes. We recognise that the engagement activities, facilitated through our Community Alliance, are an integral aspect of the research process. Moving forward, we plan to maintain our momentum by continuing to nurture our relationships through an engagement and research process that is responsive to the needs of the community, to help us realise our shared vision of improving the mental health and wellness of youth in the community.

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## Appendix Community Action Plan

Goal #1	Improving access/willingness to access mental health (MH) services
Objectives	<ul style="list-style-type: none"> <li>• To improve awareness in the community about existing MH support/services.</li> <li>• To have a mechanism for regular updates to the community on MH services for youth.</li> <li>• To develop a partnership between the school and health centre to assess and detect MH needs of the youth.</li> <li>• To provide the right service to the right child at the right time in the right place.</li> <li>• To lessen or remove the perceived stigma of mental illness within the community at large and, in particular, among our young people.</li> <li>• To empower our young people to be spokespeople of a new view of MH.</li> <li>• To enlist the parents and professionals in the community in the campaign to reduce stigma.</li> </ul>
Strategies	<p>School-based:</p> <ul style="list-style-type: none"> <li>• Ensure that the teachers in our community have the training to recognise risks and symptoms in the children and know how to best address these issues.</li> <li>• Create a school-based anti-stigma campaign.</li> <li>• Offer creative and safe opportunities to explore the issues surrounding MH through art or music.</li> <li>• Encourage peer support groups/MH days in the school.</li> <li>• Facilitate the participation of other professionals/community members in the life of the school.</li> </ul> <p>Clinic-based:</p> <ul style="list-style-type: none"> <li>• Expand the existing MH services offered through the health centre.</li> <li>• Consider outreach services based out of the clinic.</li> <li>• Explore how to facilitate access to and/or develop MH crisis services.</li> </ul> <p>Community-based:</p> <ul style="list-style-type: none"> <li>• Foster a support group for the youth of the community.</li> <li>• Create a community-based anti-stigma campaign.</li> <li>• Advocate for the MH needs of youth in the community.</li> <li>• Explore the optimal use of social media to influence attitudes and disseminate information to the community.</li> <li>• Facilitate access to resources for parents to help them cope with the problems faced by the youth of the community.</li> <li>• Promote the use of local resources for existing MH support/services and continue to develop others as the need arises.</li> </ul>

## Appendix continued

Goal #2	<b>Keeping our youth happy and healthy</b>
Objectives	<ul style="list-style-type: none"> <li>• To promote the well-being of our youth in all aspects of development (mental and physical).</li> <li>• To ensure they are given the tools to help deal with the challenges they face.</li> <li>• To ensure they have access to effective role models, including both peers and adults.</li> </ul>
Strategies	<ul style="list-style-type: none"> <li>• Develop a 'mentoring' program for youth in the community.</li> <li>• Involve and encourage youth to participate in all aspects of the development of any initiatives.</li> <li>• Involve family units at all levels where possible.</li> <li>• Directly address the issues involved in the transition to high school.</li> <li>• Develop programs that include children with varied interests appropriate to their level of development (i.e. sports/non-sports related).</li> <li>• Develop programs that improve students' life skills (e.g. career, self-esteem).</li> <li>• Encourage and support youth community leadership.</li> </ul>
Goal #3	<b>Build the community's own resources for the well-being of everyone</b>
Objectives	<ul style="list-style-type: none"> <li>• To encourage the continued development of a self-sufficient and responsive community.</li> <li>• To encourage the participation of all age groups of the community in the future direction of the community.</li> <li>• To strengthen the role of the Community Board as the promoter of participation in the life of the community.</li> </ul>
Strategies	<ul style="list-style-type: none"> <li>• Create a community-led parent resource group that will provide support and information for parents of youth within the community.</li> <li>• Provide information nights or skills workshops for youth and/or adults in the community.</li> <li>• Form an action group whose mission is to advocate for resources for youth MH and wellness in the community.</li> <li>• Create a mechanism for youth to anonymously submit ideas and feedback about youth activities and programs.</li> </ul>