

IT STARTED OVER COFFEE; THE ABORIGINAL COMMUNITY YOUTH RESILIENCE NETWORK (ACYRN) IN MI'KMAQ AND MALISEET COMMUNITIES OF ATLANTIC CANADA

DAWN CALDWELL
APRIL MALONEY

INTRODUCTION

April Maloney and Dawn Caldwell both live in Halifax, Nova Scotia. Since 2003, they have worked together to develop a project that would examine resilience to suicide among Aboriginal youth. First, with funding from the Ottawa ACADRE (<http://www.cihr-irsc.gc.ca/e/27071.html>), they worked with two communities to develop a culturally appropriate research questionnaire for youth. Once the questionnaire was finalized, Dawn and April met with other communities in Atlantic Canada, to discuss youth resilience using the questionnaire they had completed and inviting communities to join them in a community based research project. In 2005, the Aboriginal Community Youth Resilience Network (ACYRN) was funded, allowing 10 communities in Atlantic Canada and 8 communities in Alberta to research youth wellness using the questionnaire first developed by Dawn and April. This article cov-

ers some of the issues that Dawn and April faced in growing their research idea into a research network.

INTRODUCING OURSELVES

April: I am from the Indian Brook First Nation in Nova Scotia and moved to Halifax several years ago to begin my studies at Mount Saint Vincent University (MSVU). I enrolled in the Peace program at MSVU where I studied peace researchers and peace movements around the globe. One of the highlights of my time at Mount Saint Vincent was attending the Hague Appeal for Peace conference in Holland. Also during this time I was enrolled in a video editing course at a local community college. Our instructor was a local Native film maker named Cathy Martin. One of Cathy's main concerns and topics for our video editing course was suicide in Native communities. During our course we worked with footage from different communities concerning suicide. It was soon after this course that I began working with CIETcanada. I am currently research coordinator for ACYRN in Atlantic Canada.

Dawn: I am a non-Aboriginal born in Perth Andover, New Brunswick. In my 50 plus years I've been a waitress, a secretary, a student, a bank manager, and now finally a researcher and once again a student. Since 1998, I have worked with CIETcanada, an NGO that conducts research and teaches others how to conduct research. I have worked with CIET in Canada, Pakistan, Zambia, Nigeria, and South Africa. Most of my work with CIET has been done in a nonacademic setting. One of the first CIET projects I participated in looked at youth resilience in Newfoundland Labrador and I have been interested in youth resilience ever since. I am currently enrolled in a PhD program offered by CIETcanada.

FIRST OF ALL, HOW DID YOUR RESEARCH COLLABORATION START?

April: I first met Dawn when we worked together on the on-Reserve Canadian Prenatal Nutrition Program (CPNP) evaluation in 2001, a CIETcanada project funded by the Assembly of First Nations. We visited a sample of 87 Aboriginal communities across Canada to evalu-

ate the impact of the CPNP on the prenatal and postnatal health of mothers. I interviewed new mothers in my community and conducted focus groups about the CPNP with women in other Atlantic Canada communities. It was my first experience with this kind of work and I enjoyed the interaction of doing research in my community.

Dawn: Just as the CPNP project was wrapping up, the ACADRE centre in Ottawa offered seed grants to support the development of community based research. April and I had been looking for ways to work together again and this ACADRE seed funding seemed a way we might be able to. We applied for, and received, a seed grant of \$50,000. Our research topic was youth resilience to suicide.

WHY SUICIDE?

April: The issue of suicide in our communities has been sitting on the back burner for some time now. Growing up on a reserve you hear the word suicide at a very young age. I know I did. Still, although I had heard about suicide and was aware of death at an early age, it was not until a friend committed suicide at the age of 17 that the word suicide grew legs. I say grew legs because after that, suicide was no longer just a word, it was now something different for me; it was now something that moved. Who was safe? I first talked to Dawn about researching suicide one afternoon over coffee with my sister Cheryl. A young woman in our community had recently committed suicide and Cheryl and I were talking about what could be done.

Dawn: For me, listening to April and Cheryl was both moving and motivating. I was familiar with the topic of youth risk-taking in general from my two years with CIET in Labrador (1998–99) and youth resilience was the topic of my master’s thesis. I felt we could contribute to youth wellness by merging CIET’s research methods¹ — a mixture of modern epidemiology and participatory research — with the knowledge and experience of communities.

We decided to take a different look at suicide prevention or rather we decided to look at suicide risk as something that might be eliminated or reduced before it ever becomes a threat. We were interested in

1. The SEPA model: CIET’s approach to communication; http://www.ciet.org/en/documents/methods_docs/2007913105646.pdf

developing “upstream” (Saucier and Janes, 2003) interventions that could protect youth from suicide before they ever reached the point of making an attempt. We wanted to know the differences between those who were resilient to suicide and those who were at risk and we wanted to focus on “upstream” interventions that communities could implement. We knew this would be a sensitive issue; however, we wanted to develop a nonthreatening, realistic, and culturally appropriate questionnaire that asked youth not only about suicide but also about the circumstances they face in their daily lives; their exposure to drinking, drug use, and violence; their relationships with their parents and their peers; whether they felt safe; and whether they feel loved and supported and connected to their communities and culture. Several questions deal with each of these themes in the ACYRN questionnaire. Each theme provides information that can be related to risk of suicide but can also provide communities with general risk-related information about their youth.

For example, the theme of alcohol abuse included questions such as: 1. In the past six months, how often did you drink alcohol, with responses ranging from not at all to four or more times per week; 2. When you drink, how many drinks do you have? (A drink equals a bottle of beer, a glass of wine, or one ounce of hard liquor) with responses ranging from one or two drinks to ten or more drinks; 3. Do you want to stop drinking or reduce the amount of alcohol you drink; 4. It is easy to say no when my friends offer me alcohol; 5. Most of my friends think it is okay to drink alcohol (Babor et al., 2001). Our goal was to identify from these theme areas, the things that keep youth healthy.

April: Yes, keeping youth healthy is really what we want to do. We want to learn from young people in our communities who are resilient how we can better protect those who aren’t resilient.

HOW DID COMMUNITIES PARTICIPATE IN THE QUESTIONNAIRE DEVELOPMENT?

April: We worked initially with two communities, one in New Brunswick and one in Nova Scotia. Participants in the community discussion groups were selected by the community and included both those who worked directly with youth as well as parents. One of the members

had lost a child to suicide. We held a number of meetings with each community individually and a final meeting with both communities to review our finished document.

Dawn: In terms of the meetings themselves, we prepared by reviewing existing research publications about youth suicide to develop a list of behaviours/circumstances believed to be related to suicide. We used our literature review only to guide our discussions not to limit them. For example, we might begin our community meeting by talking about substance abuse and that discussion would lead naturally into another area related to youth wellness. We used questions from existing studies whenever these were culturally appropriate.

April: Deciding on the contents of our survey was only the first step. We also needed to ensure that our questions were culturally appropriate. This involved a review of all the questions and responses by the community working groups. The questionnaire was finalized with this review. We then tested the questionnaire with two groups of youth aged 12–15 to make sure that our questions were understood by the age group we wanted to interview. If changes were made to the questionnaire content at this point, it was only to clarify wording for younger respondents.

Dawn: Along with questionnaire content, during our meetings we also discussed the methodology we would be using to conduct interviews within the community although at this point, we did not have funding to actually do the surveys. It was extremely useful to discuss such issues as parental consent and confidentiality at this point because we were able to incorporate the outcome of these discussions into our future funding proposals, one of which led to ACYRN.

These community discussions also informed our submissions for ethical approval. The questionnaire and methodologies for creating the questionnaire were first approved by the Ottawa ACADRE ethics committee, an all-Aboriginal body made up of delegates from the Assembly of First Nations, Inuit Tapiriit Kanatami, the Métis National Council, the Native Women's Association of Canada and the Congress of Aboriginal Peoples. A second review of the questionnaire and methodology through CIETcanada's ethics review process incorporated the new CIHR guidelines for Health Research Involving Aboriginal people.

WHAT IS ACYRN?

Dawn: ACYRN stands for Aboriginal Community Youth Resilience Network. ACYRN was the happy result of our third attempt to get funding to use our youth risk questionnaire. ACYRN is a research network that focuses on keeping youth safe from suicide. Most suicide-related research involves interviewing those who have already attempted suicide or are seeking help because of the way they feel. As they receive help, they also supply information; but what about input from healthy youth?

In ACYRN we wanted to look at things differently. In ACYRN our focus is resilience. Our survey contained 102 closed-end questions about parental monitoring (Fletcher et al., 1995), parental communication (a seven-item scale developed specifically for the ACYRN youth survey based on input from community working groups) as well as scales to measure social support (Galambos and Tilton-Weaver, 1998), self-esteem (Rosenberg, 1965), mastery (Pearlin and Schooler, 1978), and distress levels (Galambos and Tilton-Weaver, 1998). Whenever possible and appropriate, questions from existing literature were used. We started by identifying those youth not at risk of suicide. We identified resilient and nonresilient youth from three questions about suicide: 1) Have you ever attempted suicide; 2) In the last 30 days have you thought about ending your life (with responses ranging from never to many times); and 3) In the last 30 days how often has “feeling blue” (being sad) bothered you. Once we have identified the “resilient,” we can describe the things that make them resilient; things like having a good relationship with parents and friends and feeling safe. This might be considered the “knowledge building” component of ACYRN where we try to build a picture of “resilient” youth. There is also a “knowledge use” component built into ACYRN. Once we know what factors increase resilience to suicide, we then discuss this information with the communities.

ACYRN provides a framework where researchers and partner communities can get to know each other. This doesn't happen overnight. April and I came together over five years ago with different strengths. We combined our knowledge with that of communities to develop our questionnaire. Now with ACYRN, we have a chance to grow these community/researcher partnerships even more.

April: When we go to the communities with our results, it's not enough to just talk about what keeps youth well. We need to be able to shape this information into possible interventions for the communities. For example, in a community meeting, we might discuss how feeling cared for by a parent decreases risk of suicide. We found in our study that youth who feel cared for by their parents were only a third as likely to be at risk of suicide compared to youth who don't feel cared for.² We want this finding to lead into discussions about how the community can make a difference by channeling its resources to improve parenting programs. Communities do have solutions. ACYRN provides an environment for recognizing this.

CAN YOU EXPLAIN WHY ACYRN IS DIFFERENT FROM OTHER PARTICIPATORY RESEARCH PROJECTS?

1. ACYRN GIVES VOICE TO SMALL COMMUNITIES

Dawn: ACYRN provided an opportunity for small communities to participate in high quality research. Size often limits the type of research Aboriginal communities can do; small populations may never make it into a quantitative research loop. ACYRN was an opportunity for 382 youth in New Brunswick and Nova Scotia anonymously to pool their information into a larger data set. This made it possible to look at some very specific community dynamics, and to consider wider trends across all the participating communities.

April: It's a good combination for small communities, being able to give quantitative input about resilience by joining with a larger group of communities but still being able to decide independently how to react to the research findings.

2. ACYRN SUPPORTS LONG-TERM PARTNERSHIPS BETWEEN COMMUNITIES AND RESEARCHERS

Dawn: ACYRN is a community research network. Let's talk a moment about the differences I see between a research network and a research project. In a research project we usually have one kick at the can. We have a topic that we want to learn about. We develop our instruments and

2. OR 0.3; 95%, CI 0.1-0.7 implying 70% protection.

methods to collect information about that topic. We do our analysis and we report our findings. In this one-shot environment, capacity building within communities will always be limited.

April: I can agree with that. As a community-based researcher, that was exactly my introduction to research. I just got my feet wet and it was all over. Because ACYRN lasts five years, we are able to give our Community-based Researchers (CBRs) a lot more training and not just about data collection. We've had a series of two-day training sessions about doing literature reviews, questionnaire development, data entry, and preliminary analysis. And we are always talking about what we learned, why things didn't go as planned, why they did go as planned. Most important of all, we get another chance to improve our look at youth resilience.

Dawn: That's right. Now we are preparing for a second round of surveys in the ACYRN communities. You might wonder what else there is to learn about resilience after our first round. Didn't we learn all there was to know then? Well, we did learn a lot about resilience and some of what we learned made us want to go back and ask different questions. That might sound like trial and error, and I would agree to some extent, but consider how much has changed since we last talked with community youth.

April: Things have changed! Take bullying for example. We know from our current survey that youth who feel safe are at less risk of suicide compared to those who don't feel safe.³ We also know from our current work that feeling safe is closely related to bullying. A child who is not bullied is more likely to feel safe⁴ and because of this, they are less likely to be at risk of suicide. In our first survey, we asked youth about physical violence and being threatened but since that time, the internet, text messaging, and cell phone cameras have all become electronic bullying devices. This type of bullying may even be worse because you can't escape it. You can't avoid this type of bullying even when you're home and should feel safe (Wolak et al., 2007; Agatston et al., 2007). We need to ask youth about this. It's a huge change in their environment.

3. OR 0.2; 95%CI 0.1-0.6, implying 80% protection.

4. OR 2.5; 95%CI 1.4-3.3, implying 60% protection.

Dawn: Each time we discuss our work, it becomes better, more relevant. We always view our work with a critical eye, looking for ways to make it better. This reflection occurs in all research projects. In ACYRN, we are lucky enough to be able to act on our reflection. We are lucky to be able to revisit and refine our questionnaire to build it into a sort of resilience inventory for communities. At the same time, we are getting a clearer picture of the issues involved in conducting community surveys.

April: Let's not forget we learn by practicing. Like Dawn mentioned earlier, most projects provide the community-based researcher with few chances to strengthen what they've learned through practice so skill building is limited. This is not so much the case with ACYRN. Community-based researchers participated in questionnaire development, they completed data entry,⁵ and they've received an introduction to analysis. Future sessions will involve the CBRs and community members in more discussions around the ethical issues of consent and protecting the anonymity of participants.

3. ACYRN ESTABLISHES COMMUNITY TO RESEARCHER AND COMMUNITY TO COMMUNITY LINKS THAT WILL EXTEND BEYOND THE FUNDING LIFE OF ACYRN.

Dawn: We've touched on this before but one of the benefits of ACYRN is the opportunity it has given us to forge strong relationships between researchers and communities. Researchers and communities will want to work together again on resilience or other issues. Those partnerships are already well established under ACYRN.

In terms of partnerships this is a good opportunity to talk about data stewardship and ownership. Under ACYRN, CIETcanada is responsible for the stewardship of the data (supervising the data collection and analysis, storing of the original survey instruments). Communities retain ownership of the data (how findings are released and to whom) as outlined under OCAP (Ownership, Control, Access, and Possession).

April: I think communities will also be in a better position to use and understand all research they encounter because of their ACYRN ex-

5. Data entry was completed using *Epi Info* software; <http://www.cdc.gov/epiinfo/>

periences. They will have the ability to critically assess proposals and decide about participating in future research projects.

DO YOU HAVE ANY COMMENTS ABOUT GETTING FUNDING?

Dawn: First of all, building a research network with communities is a continuous process. In our case, it began with the questionnaire development and grew into ACYRN. We could say the questionnaire development was the first phase and ACYRN, the second. What happens in between? Well, the relationship building doesn't stop. How could we work with communities to develop this questionnaire, invite still more communities to take part in a multicomunity survey and then stop everything because of funding? Momentum is not a word I would normally use when talking about research; however, in our case, it was indeed important. When we had funding, we had momentum. In those periods when we had no funding, momentum crashed. This was especially hard when we already had a community-developed questionnaire we were ready to use.

April: I agree. Building partnerships with communities is a continuous process that can not start and stop with funding. I made many trips to our communities during that funding search to maintain contact and update them on our funding progress. Our partner communities remained supportive but life goes on and things change. Sometimes the community person I'd been working with for a year would be unable to continue their involvement so I would use my visit to introduce myself to our new community partner. We would start from scratch, going over the questionnaire and talking about why we asked what we asked. There were times I wondered just how long we'd be stuck in this holding pattern. Fortunately, CIETcanada was able to fund our work in some communities during this period.

Dawn: Yes, CIETcanada did fund our community research during that funding crunch. Remember that we did not know if or when we would get funding for our youth resilience project so CIETcanada decided to proceed on a smaller scale; continuing to lay the foundation for the network ACYRN would eventually let us build.⁶ Without this larger fund-

6. Completion of surveys in Atlantic Canada occurred in 2004–2005; in Alberta, in 2006. Second round of surveys in Atlantic Canada being completed May–June 2008.

ing we could never have built the skills we have built under ACYRN, but while we were trying to get the funds April was able to proceed with design, some of the data collection and community interactions.

ACYRN STARTED IN 2005. CAN YOU GIVE US AN IDEA OF WHAT HAS HAPPENED SINCE THEN?

Dawn: We now have a total of 18 communities involved in ACYRN, 10 in Atlantic Canada and 8 in Alberta. This might be a good place to talk about the two arms of ACYRN because it shows how flexible ACYRN can be and, actually, has to be.

Overall, ACYRN represents an inquiry into quite a complicated subject — resilience to suicide. With a lot of discussion in the first two participating communities, we first translated that inquiry into a questionnaire format. We then took our questionnaires into other communities interested in the same inquiry. Given the complexity of the subject and the uniqueness of each community, we considered our questionnaire to be only a starting point for the discussion with each community. Communities could veto questions or add questions related to youth wellness. Communities were also able to decide what age groups they wanted to include in their survey. After detailed discussion, most of the communities opted for the same questions.

We were able to test the flexibility of our questionnaire in a completely different setting with the Métis Settlements in Alberta. These communities wanted to include an older age group than we had done in Atlantic Canada and they wanted to add resilience questions that were appropriate for them. ACYRN allows individual communities to add relevant questions and to exclude questions not deemed appropriate. The core questions about substance abuse, exposure to violence, relationship with parents, friends, community ties, culture, and spirituality remain the same from community to community; however, if communities wish to exclude questions about sexual violence, for example, this does not prevent the inclusion of data from the questions they *do ask* in a larger data set for analysis purposes.

April: Since we had already completed the data collection in Atlantic Canada, we could immediately move into other topics for training using the data we had already collected. We have had 6 two-day training sessions for CBRs. On average, 5–7 people attended each training

session. Training sessions covered the steps in a typical CIETcanada research cycle: framing the research topic, reviewing existing literature about the topic, questionnaire design using questions from the literature when appropriate, data collection methods, data entry, data analysis, and interpretation of the results into evidence-based actions communities may undertake. Future sessions will reinforce data collection methods, data entry, data analysis, and interpretation of the results. In the last of these sessions, we reviewed the questionnaire, question by question, to delete or reword what hadn't worked in our first data collection.

Can I say our sessions are fun? We talk about our own work but we also talk about research in general. Dawn brings in examples of research from articles she cuts out of the newspaper and we talk about them sometimes line by line. Some of the articles are quite funny and Dawn uses them to make a point. We laugh a lot and it's a very friendly chatty environment. The articles were taken from two national newspapers; the *Globe and Mail* and the *National Post*. The articles varied in content and length, some offering only a summary of the research findings, others offering more in-depth coverage on a variety of topics. These articles generated discussions about research; how it is reported, what it actually means, and, when available, the methods used. Many of the participants are first-time researchers who find themselves puzzled by the process, until they have their "Aha!" moment and see how research can make sense to them and add value to their communities.

Dawn: I think this has a lot to do with the way I learned to do research. There's always something that sticks in your head, that one comment, expression, or story about research that suddenly makes the light bulb go on. I still remember some of the anecdotes and methods that helped me in my early learning. And I'm still learning. When we do research and we talk only with other researchers, we sometimes forget how to talk to "normal" people. We like to call a spoon an eating utensil. We expect this from other researchers. There may be a scientific reason for our choice of words but if the rest of the world calls it a spoon, I think we as researchers need to adapt to that, especially if we want our work to be useful to others. ACYRN has been a wonderful environment for me to build a more meaningful vocabulary.

WHAT'S NEXT IN ACYRN?

Dawn: In both Atlantic Canada and Alberta, we are ready to undertake a second round of surveys in our communities. One of the things we learned in our first round is that youth don't seem to be as interested in talking to us as we are to them. By making arrangements with community schools, we found it quite easy to interview kids in their classrooms. It was much harder to reach the young people not in school. Consequently, we can say very little about their resilience to suicide or if attending school in itself has an effect on resilience.

April: We attempted to involve kids who aren't attending school by holding evening events with pizza in some communities but this didn't work as well as we'd hoped. The young people who don't attend school, often don't attend evening events either or at least not in our case. We really need to take a look at this with the communities. This is one of the areas where communities can really lend support.

Dawn: After this second round of surveys, community-based researchers will again enter and validate the data and participate in analysis sessions and all through this process we will be reinforcing the things that were learned in the first cycle. We will also be re-evaluating the effectiveness of our instrument a second time. We will find out if our additional or altered questions have improved our ability to understand youth resilience.

April: Others in the community learn from this besides the community-based researchers. CBRs spend much of their time understanding the mechanics of doing research. Health directors, youth councilors, teachers, and other community members spend more time on the research findings. They may be better equipped to convert the findings into possible interventions.

Dawn: ACYRN results do not always lead to prevention programs as researchers or policymakers envision them. We encourage communities to relate their experiences resulting from this research in their own time using their own methods. In the next two years of this round of funding for ACYRN, we also want to focus on future research — particularly measuring the impact of whatever ACYRN communities decide to do with their evidence. But research skills still come to very little without funding. Communities have joined together to do

research under ACYRN, some perhaps for the first time. With these relationships established, future research collaborations can happen more easily between them. We want to discuss any research ideas that arise from our current resilience work in ACYRN and look at ways we might develop them into fundable projects in the communities after this round of ACYRN is over. ACYRN may help to redefine the funding criteria for community-based research by our performance and evaluation.

ANY FINAL THOUGHTS?

Dawn: There is one other opportunity that ACYRN offers us and that is the chance to test whether or not community interventions have affected “youth resilience.” Let’s talk about this using an example we used earlier. We found that youth who felt cared for by their parents were at less risk of suicide. This knowledge might encourage a community to enhance its existing parenting programs or start one if none exists. What we often aren’t able to do is find out if interventions actually worked. Did the improved parenting program actually increase youth resilience? In ACYRN, we have the opportunity to carry out this evaluation. We will have the first opportunity to do this after we have completed our second round of data collection. We will then be able to measure whether any activities/interventions undertaken by communities between the two rounds of data collection have affected youth resilience. This evaluation allows communities to channel resources into things that are shown to work.

April: So far, we have held sessions for community-based researchers in Atlantic Canada and Alberta. A joint session for the two groups is planned in the final two years of ACYRN where we can share our experiences. It will be really helpful to hear what everyone else is doing.

Dawn: And finally, have patience. It took over two years and several complex proposal packages before ACYRN was funded. From the start, utilizing our community-developed resilience questionnaire was our goal. We proceeded to answer any call for proposals that fit what we wanted to do. You need to be creative. Being turned down was a valuable part of my capacity building. The third proposal was a lot better

than the first. I guess my point is, do not be disheartened if your request for funding is turned aside. Take a deep breath and try again.

REFERENCES

- Agatston, P.W., Kowalski, R., and Limber, S. (2007). Students' perspectives on cyber bullying. *The Journal of Adolescent Health* 41(6 Supplement 1):S59-60.
- Babor, T.F., Biddle-Higgins, J.C., Saunders, J.B. and Monteiro, M.G. (2001). *AUDIT: The Alcohol Use Disorders Identification Test: Guidelines for Use in Primary Health Care*. Geneva, Switzerland: World Health Organization.
- Fletcher, A., Darling, N., Steinberg, L., and Dornbusch, S.M. (1995). The company they keep: Relation of adolescents' adjustment and behavior to their friends' perceptions of authoritative parenting in the social network. *Developmental Psychology* 31:300-310.
- Galambos N. and Tilton-Weaver L.C. (1998). Multiple-risk behavior in adolescents and young adults. *Health Reports* 10(2).
- OCAP (Ownership, Control, Access and Possession or Self Determination Applied to Research: A Critical Analysis of Contemporary First Nations Research and Some Options for First Nations Communities http://www.research.utoronto.ca/ethics/pdf/human/nonspecific/OCAP_principles.pdf
- Pearlin, L.I. and Schooler, C. (1978). The structure of coping. *Journal of Health and Social Behaviour* 22:337-356.
- Rosenberg, M. (1965). *Society and the Adolescent Self-Image*. Princeton, NJ: Princeton University Press.
- Saucier Lundy, K. and Janes, S. (2003). *Essentials of Community-based Nursing*. Sudbury, MA: Jones and Bartlett.
- Wolak, J., Mitchell, K.J., and Finkelhor, D. (2007). Does online harassment constitute bullying? An exploration of online harassment by known peers and online-only contacts. *The Journal of Adolescent Health* 41(6 Supplement 1):S51-8.

