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Grey Matters: a guide to collaborative research with seniors

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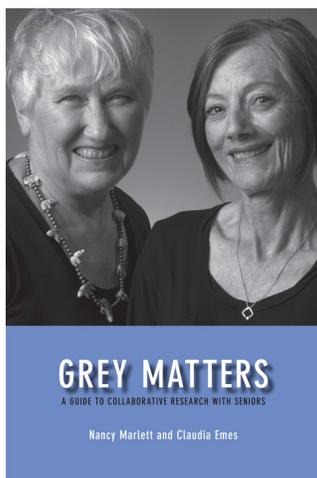
GREY MATTERS
A Guide to Collaborative Research with Seniors
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Making a difference.
Making you think.

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READY:
Setting the Agenda for Your Research

Take your time getting ready for inquiry and research, for this is your foundation. Shoddy or rushed preparation may get you to the starting line faster but may get you to the wrong race altogether. Community-based research is inundated with "hurry up and wait" research, conceived to meet the needs of a funding body. This process is generally called RFP or requests for proposals, which are initiated when a funder has a particular issue they need input on. The proposals can languish in the in box until funding is approved or guidelines are finalized.

The following steps will help you sort out what you are interested in so that you can respond to requests for proposals with confidence or start your own inquiry process without formal funds. The steps are: A. engage with your topic and other seniors, B. clarify the issue or opportunity, C. attract other partners.

A. Engage with Your Topic and Other Seniors

> I was really upset and didn't know if I was the only one who was concerned. Then I found out that it was worse than I thought from my neighbour and I went and talked to the manager of another building who confirmed that it was a problem. She told me to get more information and more people involved. (CJ, 2006)

If you feel alone with a concern you may give up in the face of the enormity of the problem. Before you do anything, talk with other seniors. The following are some of the ways that you can connect with them:

Form an informal network of concern. Find a friend or two to start an informal network by word of mouth. Spend time thinking together about what is bothering you and what you hope to achieve. If you decide to proceed, talk to people in charge at a centre, club, or group that could provide a place to meet, sponsorship, and perhaps even the use of official letterhead.

Contact retired professors. Most universities and colleges have an association of retired professors that sometimes are called emeritus professors to denote that they have made a significant contribution to the university. We found this group to be a wonderful source of seniors with a love of research and a willingness to help others get involved in research.

> I was pleased to be invited to join the Kerby Centre of Excellence. You can look at research that isn't restricted by the university; you can be wider in scope. The biggest part is having the time to enjoy the research itself, and to touch things that you haven't done before. (HB, 2006)

Hold information meetings. Advertise to find people who share your ideas so that you can get together and discuss ideas. It is helpful to have someone prepare a talk about your concerns from a senior's perspective. The following quote is from a related project in Cochrane.

> We had a small group of us interested in elder abuse in Cochrane, so we got someone from Kerby to come out to talk about abuse with our seniors. From these meetings, we saw that our seniors were also being abused. We got the institutions involved, some of the seniors were interested particularly in bullying and then the council and the local government got involved. It was no longer just a few of us. (MW, 2005)

Organize your inquiries: The following are some of the ways that you can create a record of your work so that when it comes to writing proposals or reports, you can find your ideas and contacts.

Take minutes. Set up a notebook or computer folder and take notes as if you were a secretary taking notes at a meeting. Have someone in the group designated as the scribe so that you can trace your ideas, referring back to what was happening when decisions were made and who was involved when topics were discussed. One effective way to take notes is to send e-mails to the group about what you did and invite them to reply. You can then save e-mails at each stage and print them out if you want to keep track of what is happening in hard copy.

Create Files. As you begin to gather information, start a file box. Separate personal stories, articles (by topic), and policy statements (by level of government) from notes taken on events. It is very useful to have the files in a common area where everyone can see what is happening.

B. Clarify Your Shared Concerns

Once you have a better idea of your concerns or opportunities, you are ready to test out your ideas. This includes collecting short narratives, looking at your concerns as a social problem, systematically collecting information and contacts, and finally testing your motivation for conducting research. This is likely the most interesting but most time-consuming aspect of conducting research, but it will move you from "a token senior at the table" to "a partner with information to share".

Observe, listen and document personal stories.

Listen carefully to the stories of people who live your topic (elder abuse, lack of access to transportation, loneliness, training for a marathon) and begin to collect these stories using the methods described in Chapter 6 (Narrative Interviewing). The following quote shows how a personal story calls out to research and action about elder abuse:

> There were all these calls from seniors that really bothered us. One old fellow had his nephew visit and take his bank card. The nephew was stealing from the old guy. He called us because his nephew hit him when he tried to get his bank card back. So many of these old folk are afraid because they have no one to help them out so they take the abuse. (CJ, 2006)

Personal stories define the problem you are seeking to understand, illustrate issues, and can be used in reports and proposals. By connecting to the stories of seniors, you stand with them and this is what distinguishes senior researchers from other researchers. The following is an example of a vignette – a very short story about elder abuse.

Granny Joe, as she was known in the community had been a keen supporter of children in need her whole life. She moved in with her son when he moved back home after a failed business in the city. She looked after their three children until the children grew up and she grew frailer. She seemed to withdraw from her community friends and when Betty, the eldest daughter, returned home for a visit, she was shocked at the fear she saw in her gran's eyes. Granny Joe went to live with Betty and much later Granny Joe confided that she had been frightened for years by her son, both emotionally and physically. Betty decided not to intervene but stopped visiting her brother.

As volunteers and staff at Kerby were collecting stories, the federal government, through Health Canada, was looking to research elder abuse. Kerby was invited to become part of the national initiative because of their earlier work on identifying the stories of abused elders. Kerby was able to interview another 100 abused seniors because of its reputation in the field.

From these interviews Kerby developed a report on the 100 cases and wrote a manual called *Golden Years: Hidden Fears* for frontline helpers (available through the Kerby Centre for a nominal sum). The purpose was to define abuse and supply a list of resources in Southern Alberta. It also declared that Kerby was at the table in setting policy and program agendas about elder abuse.

It is hard to collect stories on topics such as abuse and isolation because people often hide when they are embarrassed or frightened. You may have to use other seniors or a local service such as Meals on Wheels to find people that might be abused or isolated. Chapter 4 (on doing field-work) will help you think about the ways that you might observe and listen, to identify what the problem or opportunity is and how to define it.

Frame your issue or question as a social problem.

> We knew from pulling the records of calls made to Kerby that many old people were afraid of their relatives and we made a decision to pursue this further. The small group of us knew we had to follow this lead even if no one else was concerned. (NM, 2007)

A social problem is an issue that is likely to attract attention and resources. Before you invest a great deal of time and effort into turning a concern into a more formal inquiry or research project, it is wise to step back and think politically. There are thousands of issues that are important and only a few get recognized. This work can be painful for it requires that you temporarily shelve your passion and look at your issue through the eyes of politician and potential funders.

An excellent resource is Donileen Loseke's short book *Thinking about Social Problems: An Introduction to Constructionist Perspectives.* It is available through the online bookstores. The first part of the introductory chapter is reprinted as Appendix 10 of this book. It will help you separate the personal anguish you feel from the external forces that cause the problem to be ignored or addressed. This is not to suggest that you drop your concern if it is not currently or potentially a social problem. Many personal or local concerns need to be honoured and may in the future become social problems, but you may need to make other inquiries and take action to bring the problem to the fore.

There are four questions to ask yourself in deciding if your issue can be seen as a social problem worthy of being funded in your current political climate.

Does the condition you are concerned about create harm; is it wrong? One need only look at international differences related

to weight, institutional care for the elderly, marijuana use, spanking children, and same sex marriage to understand how cultural values impact social problems.

Is the problem widespread? This helps you separate a social problem (one that affects a large number of people) from a personal problem that may be very upsetting but is limited to a small number of people. You can often form alliances with others who share a similar problem to create a critical mass of concern. For example, elevator access to rail transportation is a concern for seniors, persons in wheelchairs, and mothers pushing strollers. Together they can claim that access is a widespread problem.

Can the problem be solved? Many serious issues (e.g., death, taxes, incurable disease, and natural disasters) are not social problems because there is no way to fix them. Unsolvable problems can often be broken into smaller elements and reframed, for example, premature death because seniors can't get health care, unfair taxes for seniors living in inner cities, etc. You need to think carefully how your issue might be stated and defined as a social problem that might be solved.

Should the problem be solved? There are many social issues that irritate us or seem to be important to a small group, but if the general public are not concerned, it will likely not be addressed. For example, spanking children has become a problem only in recent years and the new term "elder self-neglect" has moved frail, fearful, and confused seniors into the limelight as self-abusers. Problems are constantly being redefined to create a reason to act.

As you complete your analysis, you will have a much clearer understanding of how to frame your concern in preparation of building a more formal information base.

Collect related information.

You will likely have already found some literature related to your topic. Now is the time to conduct a thorough review of information available.

Search the Internet by topic. You are lucky to be starting a research career in the era of the Internet. There are many sources of information available. With tools such as www.google.com and www.Copernic.com you can easily browse the literature on your chosen topic or issue. The trick to using the Internet is to frame your search so that you don't come up with thousands of hits (potential sources of information). Most search engines provide guidelines to figure out how best to search. After a while, you will locate online journals that seem to address your topic and you may want to subscribe to one or two to stay connected to developments.

Connect with Consumer websites. Seniors, disabled people, aboriginals, and poverty coalitions host advocacy discussions that provide leads to good literature sources that are relevant to your search. Don't rely only on sites about seniors, as other groups have a longer history of advocacy that you can take advantage of. The following is a list of websites you can try:

- National Seniors Council (Canadian), www.seniorscouncil.gc.ca

- Seniors and Community Supports (Province of Alberta), www.seniors.gov.ab.ca/contact_us

- Canadian Pensioners Concerned Inc., www.canpension.ca

- Canadian Association of Retired Persons, www.carp.ca

- Older Women's Network; e-mail info@older-womensnetwork.org (they have an active research and education department)

- Canadian Network on Third Age Learning, www.catalist .ca

- National Council on Aging; American Association of Retired Persons, www.aarp.org; American Society on Aging, www.asaging.org

- National Institute on Aging Information Center, www.nia.nih.gov

- Canadian Centre for Disability Studies, www.ccds.ca

Don't overlook the national and provincial (or state) websites related to your topic. They provide an excellent source of current policy directions. Locate the national seniors advisory councils for their yearly report cards that provide a quick overview of what is happening to and with seniors.

Shop at booksellers' websites. A current book on your topic often helps provide a structure for the rest of your work. Websites like www.chapters.ca or www.amazon.com are good places to start.

Search university libraries. A subject librarian can help you with a library search. You may have to take out a community membership but a library card is a good investment.

You should now have a good idea as to who is currently doing the type of research you want to do. You may not agree with their findings or their approach, but it is important to know who could be your allies and your challengers. Summarize your findings under the following

headings: names, references, contact numbers, and a quick summary of their findings.

- Researchers at your local or regional (state) university

- Researchers who support your perspective in journals

- Researchers who challenge your perspective in journals

- Government policy and research allies and detractors

- Local professionals and groups that are allies and detractors.

Consider your motivation for doing this research.

This next section has been included, with some modifications, with the kind permission of Ronald J. Chenail of *The Qualitative Report*. He introduces you to how your motivation to conduct research will guide what type of research you may want to do.

With this in mind he introduces us to seven methodological families or approaches to doing research. These he calls the Seven C's: curiosity, confirmation, comparison, changing, collaborating, critiquing, and combinations. The entire article is included in the Appendix 11 if you wish to use it to facilitate group discussion. You may also want to read Chapter 1 of *Doing Qualitative Research: Multiple Strategies*, by B.F. Crabtree and W.L. Miller; it also outlines the questions of research in an easily followed manner that will help you work with academic and health researchers.

Curious: If you are curious about an intriguing topic, you might be interested in conducting an informal inquiry and you will likely approach your ideas from a qualitative research perspective that emphasizes open-mindedness and flexibility. Some of the questions

you might be asking if you are at this early exploratory stage might be:

- What is it? For example, what is elder abuse, what sorts of abuse are elders exposed to?

- Who is affected? Which seniors are most at risk of being abused?

- What is important here? What protects seniors from being abused?

Confirm: If you want to prove a theory or make predictions, you will want to use quantitative methods and control the conditions such as age, gender, and income. Some of the questions you might find yourself asking include:

- Does this theory apply to seniors? Do theories of spousal abuse apply to seniors?

- If abusers were charged, would this help seniors or put them at greater risk?

This type of research is not included in this book, but there are many ways to become involved as a partner in more formal research through your local university.

Compare: If you want to compare one group or approach with another, you would generally evaluate the differences between the two conditions you want to study. Some of the questions might include:

- What are the differences between two groups of people? What are the differences between men and women who are abused as seniors (background, lived experiences, supports, income)?

- What might account for the differences? Why are there more urban seniors in abuse shelters than rural seniors?

Change: If you want to change actions, policies, and practices that reinforce the status quo, you would approach your project from a Participatory Action Research perspective (PAR) perspective. Some of the questions you might ask:

- How might police procedures be changed to ensure that abused seniors are not left in an abusive situation?

- How can funding for women's shelters be expanded to include abused seniors?

There are excellent resources written on action research that are written for community members and are easy to understand. One of the best is *Participatory Action Research with older people: A source book* is available on the Internet at www.helpage.org.

Collaborate: If your primary purpose is to form relationships and through those partnerships understand each other's perspectives, then your research method should be a collaborative inquiry. One question you could ask is:

- How can we get seniors associations and services to work together to improve services to abused seniors?

This manual is written to promote collaborative research where the initiative comes from seniors or researchers with a deep commitment to partnership.

Critique: If you want to critique (challenge) those in power, you would chose to look at critical research methods such as discourse analysis, which emphasizes a particular stance related to values and power. Some of the questions you might ask are:

- What aspects of aging (loss of income, status and/or physical appearance) create the excess of discrimination?

- What beliefs, attitudes, or policies maintain abuse and discrimination?

- What practices create dependencies and devalued roles for seniors?

Feminist research and disability studies have created critical research frameworks that are very useful for senior's research. You might refer to *Disability Is Not Measles*, edited by Marcia Rioux and Michael Bach as an example. Over time, seniors will develop their own brand of critical analysis as aging studies becomes recognized.

Combination: One type of combination research occurs when different disciplines contribute their perspectives and methods to a common issue. Our interest in aging studies comes from our belief that it is not realistic to look at aging through one set of disciplinary glasses. We hope to encourage research that crosses disciplines while including the perspectives of seniors.

C. Attract Other Research Partners

We paired up with the Calgary Crisis Centre to set up a dedicated seniors help line. This became a 24/7 telephone line for calls requiring an outreach worker. This would allow us to gather specific information about what abuse was happening and how frequent it was. The line was jointly manned by the Calgary Crisis Centre and the social workers at the Kerby Centre. We used this pilot project to determine if this approach might work and to identify and define the need for elder abuse service. (NM, 2006)

Once seniors are engaged, it is possible to invite others who share your concern. You may not need people from each of the following categories but you should consider these resources and, if appropriate, include them early in your process. You do not need a long-term commitment at this point. You need one or two sessions to explore your thoughts and to find out what others have to offer. Some of these partners might be:

Academics and students are some of the most useful resources since they represent committed and enthusiastic labour. Students can do literature searches and community surveys or write proposals, often for course credit. An academic who is interested in your topic can bring networks and the use of university resources as well as help in writing and doing research.

Contact the community relations department at your college or university for a list of people who might be interested in your topic. Contact them early in the process because it often takes a while to set up practica where students work with you for credit.

> Students often provide a new perspective on things; very often they have unbounded enthusiasm and work very hard when they are considered part of the team. Students tend to identify with seniors, through their grandparents and this tends to be a more personal endeavour. It is a great opportunity for students to value what seniors have to offer society and that seniors contribute a lot. (HB, 2006)

Professionals. There are many sources for professionals. In the case of the elder abuse project, Kerby looked at social workers, lawyers, doctors, law enforcement groups, and educators as potential resource people.

Each project will require its own partners. Try to find professionals outside of aging. They will balance the tendency of professionals

to take the lead and will often ask the probing questions that move you forward because they are unfamiliar with the issues of seniors.

Advocates. Groups and agencies that address similar issues and problems. These might be other seniors associations, service providers, or advocacy groups. Reach out beyond your network to groups with proven track records in the work you are contemplating. Look to unions, poverty coalitions, or cultural groups who are innovators.

Service providers. An outside group can bring attention to seniors' issues. In the case of elder abuse, the distress centre was concerned with abuse but had not considered the needs of seniors, and by working together each gained.

> I was a volunteer on the social work committee when the calls about abuse were coming in. We had a meeting to talk about the calls and from that meeting we selected people from Kerby to meet with the Calgary Distress Centre. We first set up a pilot project to get more information; we were then able to add others as we learned more. (NM, 2006)

Politicians and bureaucrats. It is helpful to find someone inside the system that you are targeting for support. Cultivate the contact early so that it isn't considered an attempt to curry favour. You need to know the culture of the government departments that are most relevant to your topic. For example, abuse is most often considered to be an issue related to women and children but the Kerby Abuse Centre did not exclude older men who had been abused and this caused conflicts within the funding routes.

Someone close to retirement is ideal. They have little to lose in exploring new ideas, and they have a long history of what works and what won't work. They will also relate well to your group as they are aware of the issues of retirement and aging.

You will likely have to go to the head of the government department and ask them to recommend someone to work with. If you can,

have them recommend two or three options so that you can interview to find someone with similar values.

Community groups. While community seniors associations may be decreasing in size and influence, large retirement homes are fast becoming communities on their own. The seniors in these settings are well-organized, and management may be willing to support research by providing space and facilities.

> I met a senior from a large residence and he went around asking if people needed anything, he wasn't even on the residence council but kept everyone informed about what was happening. (HB, 2006)

Resources

An excellent resource is Donilee Loseke's *Thinking about Social Problems: An Introduction to Constructionist Perspectives* (New Brunswick, NJ, Adline Transaction, 2003).

HelpAge International: www.helpage.org/

Disability Is Not Measles: New Research Paradigms in Disability, ed. Marcia Rioux and Michael Bach (North York, ON: Roeher Institute, 1994), examines attitudes toward disability, rights of people with disability, and the perspective of disability as socially constructed. It further examines disability research questions through the lens of human rights and ethics.

Ronald J. Chenail, *The Qualitative Report.*