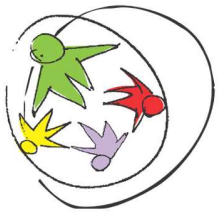

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Putting Communities First: The Power of Community-Based Action-Research for Health and Wellbeing

Address to the Communities in Control Conference
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I'm delighted and honored to have been selected as this year's International Pratt Fellow and to be part of this very stimulating Communities in Control Conference.

And I'm pleased in part because I know of no equivalent gathering anywhere in the world of so many community groups, policy makers, business leaders, and others who share a vision of the power of community for improving health and wellbeing.

I am deeply grateful to Rhonda Galbally, and Denis Moriarty for their leadership role in making this remarkable conference happen, and to the Pratt Foundation for its belief in and support of this important work.

I must confess though that as an American invited here to Australia to address your conference theme, I feel like a bit of an imposter because your country is in many ways far ahead of mine in really showing the world the meaning of healthy communities and high level community participation.

Here in Victoria, the Environments for Health framework, is one of the best documents I have seen for promoting true, intersectoral planning for public health through a heavy accent on community involvement.

I am also very impressed with the Department of Victorian Communities and its hosting of locally-based gatherings to learn about and highlight exemplary community efforts that are making a difference.

Finally, the Community Manifesto, which grew out of the first Communities in Control Conference, is a visionary blueprint for action whose reach goes far beyond Australia.

So while I'll share today some examples from the U.S. and elsewhere of the power of community groups and of community based action-research, I do so with considerable humility knowing that I have already learned from you than I can possibly hope to share.

The theme of your conference, Challenging the Power of One, couldn't be more timely. For despite a thriving international health

cities movement and numerous examples in Australia, and around the world of the value of community based work, the individual remains the focus of our health and social service systems, and to a large extent of much of what gets done in the name of improving human wellbeing.

In my own field of public health, the core discipline of epidemiology has increasingly focused its gaze on individual risk factors for disease - cholesterol, smoking, unsafe sex, etc.

Yet as my colleague, and your inaugural Pratt Fellow Len Syme is fond of pointing out: “While well intentioned, this work is almost beside the point. Lowering one's cholesterol might be a good thing to do for an individual but it does nothing to address the fact that cholesterol levels remain high in the population. Getting a smoker to quit is fine but the problem in society remains if two more youths - who still often are the targets of advertising like this (refers to slide) - begin smoking for the first time the day that first person quits.”

So among the overarching questions we’re addressing at this conference are:

- How do we reframe health and social issues so that community and society—not the lone individual become the primary focus of our efforts?
- How do we convincingly demonstrate and showcase the role that community groups and partnerships are playing in improving health and well being? And
- How do we truly put communities in control?

Although I can’t begin to do justice to all these topics, I do want to suggest one avenue that may be helpful as we think about them. And that involves demonstrating the powerful role that community groups can play in studying and addressing health and social problems through community based action-research.

The importance of broadening our gaze in this way can’t be overstressed. For whether we’re working here in Melbourne or in Sao Paolo, Capetown, Hyderabad or San Francisco, the complexity of many of our health and social problems often makes them poorly

suited to traditional “outside expert”-driven research and the often disappointing interventions it has spawned.

And increasingly community members are calling us on this fact, and pointing up what they see as a gigantic disconnect between academic research and the real concerns of citizens and community groups.

Together these forces have led to a burgeoning of interest in an alternative research paradigm that puts a heavy accent on partnering with communities, and making action to address health and social problems a central part of the research process itself … not something that outsiders do afterwards.

This alternative approach which goes by many names, has as its centerpiece three interrelated elements: participation, research and action. And in effectively bringing these three elements together we can have a powerful tool for moving forward the agenda of this Communities in Control Conference.

My favorite definition of what here in Australia is called Action-research describes it as:

> “A collaborative process that equitably involves all partners in the research process and recognizes their unique strengths. It begins with a research topic of importance to the community and combines knowledge and action for social change to improve health and well being and eliminate disparities”.

Robin McTaggart of Scotland’s Caledonia Center outlines a number of tenets of participatory action-research key among them that:

- It is a political process.
- Involves lay people in theory-making.
- Is committed to improving social practice by changing it; and.
- Establishes “self critical communities”.

Barbara Israel adds that such research involves a co-learning, capacity building process that balances research and action

And I would add that good action-research embodies a real commitment to cultural humility - the idea that while we can’t ever be

competent in another's culture, we can demonstrate a commitment to self reflection, an openness to others cultures, and commitment to respectful partnership.

And finally, good action-research also carefully attends to issues of validity and research rigor, not only in the traditional sense of those terms but also by taking a step back to ask, "is the research question itself valid' in sense of being meaningful to and ideally coming from the concerns of the community?

This last point is a particularly impressive one, because as sociologist Jon MacKinlay used to say, professionals often suffer from an unfortunate malady known as terminal hardening of the categories.

We get the kinds of answers we're comfortable dealing with because we ask the kinds of questions that will give us those answers.

But what happens when community groups actually set the research agenda or at minimum have a real role in helping to determine what gets studied and the kind of interventions that get developed?

For one thing, we're much more likely to address issue that matter locally. Professor Mughboeba Mosavel and his colleagues in South African learned this lesson when they began designing a study to look at risk factors for the high rates of cervical cancer in their country.

To their credit, these outside researchers partnered with a group of community women before proceeding too far, and as a result, the research topic was changed from cervical cancer to cervical health, reflecting the community partners' belief that HIV/AIDS, domestic violence and poverty necessitated a much broader framing of the issue if it was to have meaning in the context of their daily lives. Action-research then stresses community control in defining what it is we study.

But it also reflects another major theme of your conference, in having us move from a deficit mentality view of communities as a bundle of pathologies to instead focus on developing and epidemiology of strengths.

Some of you I know are familiar with the work of John McKnight and John Kretzmann at North Western University who've given us what they call the asset based community development approach - or ABCD for short.

Rather than simply doing community needs assessments, the ABCD approach has us collaboratively map the capacities of low income communities.

And it divides these capacities into primary building blocks - things largely under a neighborhood's control like indigenous leaders and the talents of local residents, community groups, churches and cultural organisations, and secondary building blocks - those physically in the neighborhood but controlled largely by outsiders, such as public schools, parks, or vacant land.

Once inventoried, assets like these then are used by community groups in capacity oriented community planning.

I saw this approach at work most powerfully in the low income mostly minority community in and around Richmond California, where local Health Department teamed up with community groups and residents in mid 1990's to form the Healthy Neighborhoods Project.

The project began by having residents and community groups help identify informal leaders for participation, using questions like these:

- When people have a problem, who do they go to for advice?
- Who do you go to?
- When this community has had a problem, who has come together to help address it?
- What do people tell you you're good at?

Through this method eight residents were initially hired and trained as community organisers, and more than 80 as neighborhood health advocates who in turn made up Neighborhood Action Teams.

Part of their training involved learning some health content and how to see health problems thru a broader systems perspective. But they

also were taught skills in action-research such as asset mapping and survey research.

Participants went through exercises to help them identify their own strengths, like this one in which they're indicating on butcher block paper skills they have (such as child care, cooking for large groups, and non English speaking ability—a particularly important thing to frame as a strength in context of our state's strong anti-immigrant organising.

The trained community organisers and neighbourhood health advocates then led the process in which dozens of residents, including youth, walked around the community making their own personal maps noting strengths and problem areas, and then came together to plot the risks and assets they'd identified on a collective map for use in deciding on problems to tackle and some of the resources they may have available for doing so.

They then conducted door to door surveys with 500 residents, finding out what people liked best about their neighborhood, what they wanted to see changed etc.

And they helped the health department's epidemiologist analyze the responses drawing on their sophisticated knowledge of the communities in which they lived.

The neighbourhood health advocates held a community forum where people prioritized their top goals and concerns, based on the mapping and interviews, and then went to study and work on addressing their number one issue — getting speed bumps in their neighborhood.

And because the four most important words in this kind of work are "refreshments will be served," they followed each victory with a celebration.

The HNP has had a number of important outcomes. In addition to getting speed bumps and a community center, for example, they:

- Got evening and night bus service restored in north Richmond.
- Got a defunct tenant organisation in one of the housing projects back into action and helped write $100,000 grant for a job training program.
- Got improved lighting and a youth soccer team.

And years after the failed effort to mobilize the community around tobacco, the neighbourhood health advocates took it upon themselves to get a tobacco billboard targeting minority youth removed from community.

The project created a mural capturing their vision of what a healthy community should look like, and 40 youths took great pride in paining it under direction of a local artist.

They created a bucket brigade, participating in air quality sampling and became engaged in city and regional decision making.

Now, it's difficult to determine the specific contributions of a project like this to individual health outcomes, since many different programs are operating simultaneously.

But the evaluator did show increased participation in a new child health program in participating neighborhoods, and also increased feelings of empowerment and sense of control, which we know are important intermediate level outcomes that in turn can contribute to other health and social outcomes down the line.

And I wanted to be sure to mention one of the tools he used successfully in this regard, and one I've also found very helpful, and it's a scale by Barbara Israel and her colleagues for measuring perceived control on the individual, organisation, neighbourhood and beyond the neighbourhood levels.

Here are some of the questions included in Israel's scale:

- I can influence decisions that affect my life.
- My community group or org can influence decisions that affect the neighborhood and,
- By working together, my neigh can influence decisions that affect our community.

As Dr. Syme discussed in his Pratt Lecture in 2003, there's considerable evidence that sense of control is critical to health and well being, so if we can show that our community groups and community based action-research partnerships contribute to sense of control, that's a major achievement.

Another real strength of community based action-research lies in its ability to help us design locally tailored, theory driven interventions that can make a real difference in community health and well being.

Let me give you an example. In both Australia in the US, obesity rates have doubled over the last couple of decades, and in both our counties, many factors are contributing to this.

The US for example, has been called an auto-erotic society, and all too often our communities are designed with cars, not people in mind. Where's the incentive to go for a walk when you take your life in your hands any time you do?

To be sure individual choices have a role in this problem, and we all know of kids - my 14 year old son among them - who forgo that basketball game or bike ride to exercise their thumbs on Game boy or Playstation, all the while munching chips and downing oversized sodas.

Sodas are the number one culprit in the obesity epidemic - 17 teaspoons of sugar per 20oz bottle, and in US sodas make up 15% of all calories consumed by teens.

Younger children too are bombarded with ads for unhealthy snacks - with food companies spending tens of millions to get cartoon characters like SpongeBob onto their packages.

We all know about these and other societal forces contributing to obesity epidemic, and some of them will require action on national level, such as the soda ban in American public schools that former president Bill Clinton recently helped bring about. And doesn't he look good in retrospect?

But local community groups can help us understand the specific factors in their neighborhood that may be contributing to this problem, and also whether and how local social capital might best be marshaled in design of an intervention that can make a difference.

Let me give you two examples:

The Bay View neighborhood in SF is frequently in newspapers because of problems of homicide and toxic emissions from the many oil refineries that dot the landscape.

But, when the community youth group LEJ and its health department partners did a community survey they identified food insecurity, and lack of access to nutritious foods, as one of greatest neighbourhood concerns in this area where the few local food outlets are well stocked with liquor and packaged food but carry little in way of fresh fruits and vegetables.

LEJ youth were trained to do store shelf diagramming to determine how much space was currently devoted to fast foods, tobacco and liquor. The findings from 11 corner stores were that almost 40% of space was devoted to packaged foods, and 26% alcohol and cigarettes.

Youth also developed and conducted survey of local residents about their needs and desires relation to local markets, and what it would take to get them to shop locally instead of taking business out of the community.

They interviewed local merchants to find out what it would take to get them to remove alcohol and tobacco ads, and change allocation of shelf space to provide healthy alternatives to fast foods.

And working with another community group and a local politician they developed the “good neighbor” program in Bay View - and got four city departments to endorse it.

Briefly, this program gives concessions to stores that agree to make a number of healthy promoting alternatives in the way they do business. These concessions include things like discounted loans and energy efficient appliances.

The first store to adopt new program reported an increase in sales of fresh fruits and vegetables from 5 to 15% in first 7 months, and a decrease from 25% to 15% in sales of alcohol.

And recently, five more stores in the neighborhood have signed up to become good neighbors. And building on their success, several community groups, health departments, business leaders and policy makers are partnering to pass a new state measure that would help extend this program statewide.

Again, this work all grew out of a youth group's partnership with a local health department and later other government and businesses stakeholders, to study and address a major cause of the obesity epidemic in their neighborhood.

But let's fast forward to another community, this one the small rural town of Newcastle in the middle of the country, where a healthy communities group teamed up with outside researchers to study their health situation, did a randomized survey, and in discussing the results, realized that a big cause of their high obesity rates was that the town was so spread out that people were totally dependent on cars.

So the healthy communities group mobilized their town and got young and old, business leaders and government folks, to build a network of walking and biking trails, lined by 5,000 trees, that connected schools, churches, stores, the YMCA and other points of interest.

They worked with the department of parks and recreation and other municipal departments to rebuild deteriorating public park and 1200 residents, came together and in one week built an elaborate playground and surrounding park.

And today, more than a decade after the original action-research project began, the community group is still at work, most recently negotiating with business and government partners to buy this old iron bridge, which they want to place across the highway that cuts the community in two and again is a real obstacle to walking and biking.

And when I go home I want to suggest to them that they follow Victoria's example of instituting the walking school bus notion to build on their other efforts.

I have spent most of my time today illustrating the promise of community partnerships, and here in Australia, with some 700,000 community groups, and with many government and business leaders as well as university folks, understanding the power of collaborative partnerships, the time is ideal for moving further in this direction.

But Rhonda asked me to be sure to address some of the challenges posed in this work, including how we can demonstrate that community groups and partnerships really are making a difference.

So let me turn quickly to just a few of the ethical dilemmas that arise in action-research, and then some of the special challenges in proving the value of community groups and partnerships.

A major challenge we face, of course, is that there often are power imbalances and differential reward structures in our partnerships, with professionals standing to gain more through grants, publications etc than community groups who often are expected to work for far less money and on a time table that doesn't mesh with their needs and concerns.

We also know from a study in Sydney of participation in resident action groups that one of the best ways to increase community participation lies in decreasing the associated costs.

We can do this impart by helping with transportation and childcare. But we also need to decrease member costs by making sure that community members who, often are in the position of "outsiders within," when they work with us researchers, don't in the words of Brazilian educator Paulo Freire become strangers in their own community as a result.

To address these and other potential difficulties before they arise, tribes and other groups of indigenous people in Australia, New Zealand, the U.S. and Canada have developed ethical guidelines for their collaborative work, including protocols that address:

- Negotiating with political and spiritual leaders in the community to obtain their input and their approval.

- Ensuring equitable benefits to participants (e.g., appropriate training and hiring of community members) in return for their contributions.
- Developing agreements about the ownership and publication of findings.

And in both Indigenous communities and the disability community, the maxim, “nothing about us without us” has been critical to fostering community control of the research process.

As your Community Manifesto suggests, that means in part making sure that community groups, and study participants have an authentic role in deciding how the findings will be used … and what to do if findings emerge that could cast the community in a bad light.

This is one of the tough issues that Robb Travers and Sarah Flicker in Toronto deal with in their online workshop on ethical issues in community based research, and I recommend checking out website wellseleycentral.com for a very useful tool in this regard.

I also want to highly recommend the detailed guidelines for PR which Larry Green and his partners in British Columbia developed to help us dialogue in advance and throughout the process about a whole host of about potentially challenging issues that can arise in this work.

But at the same time that we deal with these issues, we need to be mindful of the Rhonda’s other challenge, namely to document and show how community groups and their partnerships are having an effect on health and social outcomes.

This is difficult because:

- The continually evolving nature of community building efforts.
- The complex environments in which they take place.
- And the fact that such efforts often seek change on multiple levels, make many traditional evaluation approaches ill suited to this work.

We know too that changes in things like health status may take years to be able to detect - especially in a form we can attribute to a particular community group’s efforts or intervention - so it’s vital that we focus in part

on documenting changes in those shorter term system level indicators that also are critical to our work, by asking things like:

- Did our community group or project result in increased social networks?
- Did it increase community participation?
- Did it increase individual sense of control and hopefulness about the future?
- Did it result in new policies that in turn may impact on individual health and wellbeing down the line?

We can document some of these things in numerical form, using tools like the perceived control scale I mentioned earlier.

But as John McKnight always likes to remind us, while institutions learn from statistics, people learn from stories. And we mustn't forget to collect and tell the stories, and write up and publish the case studies, that show the impact of our community groups and partnerships, and the differences that they are making in the lives of real people.

Mindful of this, I'd like to close by sharing such a story, and one which was my most poignant lessons in the power of community.

When I was first teaching, a group of my students became concerned about high rates of social isolation and physical and mental health problems among low income elderly in the hotels of San Francisco suburb Tenderloin.

Residents were not allowed to cook in their rooms, but they often hooked up illegal hot plates in order to eat, and they lived in a neighborhood whose crime rate was 2 crimes per person per year.

We began by starting hotel based support groups and tenants associations through which residents could study and address problems that they collectively identified, and former a broader CBO, the Tenderloin Senior Organising Project (TSOP), to help this take place.

Not surprisingly, the residents of many of the hotels first wanted to address problem of violence.

So they called a community wide meeting, got media attention, formed an inter-hotel coalition TT-SS, met with the mayor, and got increased beat patrol officers in neighborhood.

They recruited over 100 local businesses to serve as safehouses where residents could go if being followed, and police chief later gave them much of the credit for a 26% drop in crime over first 18 months of their work.

Residents then turned attention to nutrition; starting hotel based mini markets where people could have access to fresh fruits and vegetables.

They:

- Started a co-operative breakfast program to qualify for food bank.
- Tested recipes and wrote a no cook cookbook - nutritious meals that don't require a stove.
- Started HPRC that conducted plays on health and social issues.
- Organised leadership workshops and media advocacy trainings
- Organised to get improved transportation
- Got hot water turned on in buildings that had gone 10 years without
- Got an out of court settlement against prestigious local law school that owned several buildings and had reneged on promised security arrangements.

We had lots of anecdotal evidence that this work was having effects on individual health and wellbeing:

(Refer to slide) This man was among many who quit smoking or cut back on drinking, because project made them feel they had some control and could exercise it in relation to personal well being as well.

We could also document some health changes around specific interventions - for example, using 24 hour diet recalls before and after

intro of mini markets to show increased consumption of fresh fruits and vegetables.

And we hired outside evaluator to compare health and social outcomes for 150 residents of TSOP hotels with 150 from other comparison hotels.

Using the Israel scale and other tools, he was able to show significant differences between the two groups along 14 dimensions, including social isolation, morale, perceived ability to make change in one's neighborhood, and overall quality of life.

What he couldn't show, unfortunately, were changes in hard health outcomes … in part because many of the people who made the greatest changes in health and wellbeing soon moved out of the neighborhood.

One for example, moved to San Jose where he opened a McDonalds - that one we weren't sure whether to count as a positive or a negative health outcome!

But seriously many of changes we observed were harder to quantify.

(Refer to slide) This man, when I first knew him, was shy and nervous, with a serious mental health problem, and every few months checked himself into the state mental hospital for reality orientation.

After 2 years he wasn't doing this any more and I asked why. He said: "Well, I'm a co-leader of my tenants' association, I'm a leader of TT_SS, and I'm on the Mayor's task force on ageing - I don't have time for reality!"

Now it's hard to translate this into a magic chi square, but such stories too are part of the data we need to collect and share, for they show, in most human and personal terms, the value of our community groups and partnerships.

Let me leave you with a line from Australian leader in this work, Ernest Stringer, who likes to say that community-based action-research is "the search for understanding in the company of friends."

As we go forward with our various efforts to make a difference through our community groups and partnerships, I will reflect back often and warmly on this occasion, and the company of this wonderful group of friends, who share a commitment to the power of community for making our societies and our world a better place.