Participatory Health Research with Women in Prison

Offender Health:
Who cares, who commissions, how do we make it better?
Leeds Community Healthcare, NHS Trust
20 - 21 March 2013
Marriott Hotel, Leeds
Ruth Elwood Martin, MD, FCFP, MPH
Goals

“to present your work pertaining to service user empowerment and involvement – really of the benefits to service users themselves and of course the wider healthcare service”.

➢ To share my story of this work
➢ To share some stories from women with incarceration experience who participated
Participatory Health Research with Women in Prison

1. Exploratory phase – at the beginning
2. Prison research activities – what we did
3. ‘Changed lives’ – the unexpected outcome
4. Processes – the ups and downs
5. Now, in the community
Canadian provincial women’s correctional centre
• 160 women
• 1500/year
• Medium security
• Sentenced <2 years
• Average stay 3 months
1. Exploratory phase – at the beginning

- FP, once/week prison clinics, 1994
- Continuity of care & bearing witness:
  - Substance use & IDU - HIV, HCV, cervical dysplasia; chronic illness; psychiatric illness
  - Aboriginal over representation; < gr 10 education
- Research ?s → projects → improved health?
- Spring/05: action research course
What is participatory research?

In the past, outside researchers have come into communities (that suffer from the same kinds of marginalization as a women’s prison) with their own agendas on what to research; how to go about that research; what to do with their findings (dissemination of information). All the while, missing the fact that the communities they are researching have a better idea than anyone as to what their problems are and where their strengths lie. With Participatory Research, the people being researched are acknowledged as being the experts in their own situation, and as experts of their own community.

(PR) focuses on everyone building a team on pre-existing relationships between community members (e.g. women in prison), professionals who serve those communities, and academic researchers.

Jen McMillan
PR is a process or a way of working rather than a specific methodology.

- Establishing new knowledge together
- Taking social action
- Mutual capacity building and reciprocal education
This project grew out of prison collaborative relationships - warden, recreation therapist & family physician
EXPLORATORY PHASE
(pre-funding application)

- Q1. ‘What are your most important health concerns?’
- Q2. ‘How do you see participatory action research using participatory methods working in ACCW?’

- Women in prison (17 interviews, 2 focus groups)
- Correctional officers (2 focus groups)
- Prison nurses, contractors and staff (interviews)

- Audio-taped, transcribed & thematic analysis
- Gathered interested co-investigators
Q1. Health concerns clustered into five themes:
1. Addictions
2. HIV, hepatitis and infections
3. Health care in prison
4. Life skills & re-entry into society
5. Family and relationships

Q2. Viv Ramsden - Face-to-face meeting ….to ‘member check’ & to brain-storm how PR will work in prison……PIVOTAL!!!
Face-to-face meeting

“On Oct 15/05 Dr. Martin and community-based researchers came to ACCW to ask our permission, as marginalized women, if they could put a proposal to CIHR to request funding for $200,000.00 a year for 5 years to improve health care of women in prison

Not only did we agree [N=120] we said ‘We will help put the proposal together’ [N=27]”
MEDICINE Wheel

North-White
Buffalo
North/Winter
20-60 Wisdom
Thunderbird-Fire
Mental Growth
Creator
Elder

West-Red
Medicine Bear
Evening Autumn
40-60 years prayer/guidance
Frog-Water
Grandmother Moon
Warrior

South-Blue
Mouse-Coyote
Mudbug-Summer
20-40 years Self awareness
Emotional Growth
Father Sun
Woman
Grandfathers/Grandmothers
Granny Print
Teachings

East-Yellow
Eagle
Morning-Spring
0-20 years Illumination
Turtle-Earth
Physical Growth
Mother Earth
CHILD
Shared values emerged

- Transparency of all information
- Break the code of silence
- Respect for diversity – listen and be heard
- Build on strengths
- All who wish to be involved in the research process may be involved
2. Prison research activities - what was done

- On Nov 1\textsuperscript{st}/ 2005, “We do not want to wait until the funding arrives!”
- Research became a prison work placement:
  - Up to 15 women each week
  - 200 women [Nov/05-Sep/07]
- 5 yr Research Agreement
- UBC REB certificate (Spring/06, funding results)
‘We created an orientation package’

- New member questionnaire
- Drug of choice
- Life story
- ‘Paragraph of passion’
- Confidentiality agreements, team guidelines & consent form
‘We developed a daily work routine’

- Attendance
- Angel words
- Devotional book reading (eg. AA)
- Assign team tasks and roles
- Work on our passion
- [Afternoon tea]
- Leaving certificates
Angel words

Christine ex.mpg
‘We ….’

- Wrote letters to newspapers & organizations
- Wrote proposals -> warden & funding agencies
- Organized & hosted 11 prison health research forums, Oct/05-May/07 [attendees = 800]
- Created > 60 PowerPoint health education presentations on ‘paragraphs of passion’
- Presented to 150 16-year-old high school students
- Presented to prison officers’ training meeting
- Conducted peer surveys (eg. housing, dental, nutrition, exercise, smoking, children)
‘We are gaining skills’

- Computer
- Typing and transcription
- Reading and synthesis
- Survey design
- PowerPoint
- Public speaking
- Organizational
Data collection and analysis

- Surveys, created by the women
- Thematic and narrative analysis of:
  - Life stories & field notes & writing
  - Audio-recordings & transcription of
    - prison research team meetings
    - prison health research forums
    - women’s debriefing meetings post-forum
- Descriptive statistics
- (Participatory logic models)
- (Linkage to Corrections recidivism database)
Women in ACCW engaged in participatory health research

Improved relationships with children, families & partners

Improved peer & community support

Increased access to stable & safe housing

Improved access to individualized health care

Increased job skills, relevant education & employment

Increased health & disease knowledge (IDs, cancer, illnesses, drug use effects)

Increased health awareness & integration (Aboriginal foods & traditions, spirituality, exercise, nutrition, emotional health)

Improved dentition & oral health

Improved health & to contribute to society

Improved relationships with children, families & partners

Improved peer & community support

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Improved dentition & oral health
3. ‘Changed lives’ – the unexpected outcome

- Inter-personal skills
- Problem solving
- Peer support and mentoring
- Group processing
- Increased self-esteem and self-worth
- Increased hope for success after release!
- Changed lives - entire prison community
“I was really impressed with the way the girls had put together such an informative program. I saw a side of the girls that was hidden before. It was so well put together……they didn’t realize they had these skills before. Maybe this research project has given them hope…. ”
Prison officer....

“I’ve worked here for twenty two years and thought I knew everything I needed to know… but, I’ve learned so much from your presentation.”
“….I looked up and saw those kids. They were actually listening and hanging onto my every word ….. I was letting them into my own world ….. I’m hoping I touched just one of them ….. I’ve been in denial about a lot of things in life, but today just woke me up.”
Changed lives - Kelly

Kelly 6 ex.mpg
Changed lives - Jen

Jen 3 ex.mpg
4. The processes – the ups and downs

1. Management: ↑ participatory approaches

2. Community agencies: ↑ engagement

3. Within prison (simultaneously):
   - Gardening/horticulture program
   - Mother and baby program
   - Parenting courses
   - Employment agency, CV writing
   - Computer courses, women’s studies (NVIT)
   - Programs - ‘individualized learning plans’
   - Shifting attitudes of health staff & officers
4. The processes – the ups and downs (cont’d)

5. **KEY:** Collaborative relationships (partnerships) & shared values

6. Changed lives → empowerment → system responses

7. Opened doors & closed doors: trust the process

8. Women are experts → their voice
Community Development and Empowerment

The link between personal and community empowerment and collective action (Rissel, 1994):

<table>
<thead>
<tr>
<th>Level</th>
<th>Research Type Description</th>
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<tbody>
<tr>
<td>8</td>
<td>Participatory Research, where citizens are researchers AND the researched</td>
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<tr>
<td>7</td>
<td>Observational Research, where researcher observes and ‘describes’ the variables</td>
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<td>6</td>
<td>Interventional Research, where researcher controls the variables</td>
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<td>5</td>
<td>Action Research</td>
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<td>4</td>
<td>Continuum of Research ‘Control’</td>
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<td>3</td>
<td>Eight Rungs on a Ladder of Citizen Participation</td>
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5. Now, in the community

Women in2 Healing:
‘The empowerment of women inside and outside of prison in their emotional, physical, mental and spiritual healing through participatory research processes.’
Kelly’s goal

Kelly 5 ex.mpg
Women in2 Healing

http://womenin2healing.org
http://www.womenin2healing.blogspot.com
womenin2healing@gmail.com
(closed Facebook group)
Community Projects

- **Doing Time.** Interviews with women prison leavers to understand the facilitators and barriers to achieving health goals.

- **Unlocking the Gates to Health** – peer mentoring for women prison leavers, linking them to health and social resources now catalogued on an on-line database.

- **P4H, P4C and P4HIV** – participatory preventive prison health projects with individuals with incarceration experience (IIE), Collaborating Centre for Prison Health and Education (CCPHE).

- **Bonding through Bars** – UBC international roundtable discussion. May, 2013.

2. *Living in the Shadows*. Educational video about conducting community based interviews.


4. *Doing Time*. (KT of research findings) Mo Korchinski, Director. Producer, Pull focus Film School.

5. In development - *Cancer Prevention* for IIE (individuals with incarceration experience)

6. In development – *Bonding Through Bars*
Academic Publications


Book chapters
