Enhancing Consumer Participation in a Medically Supervised Injecting Centre through Participatory Action Research

Mark Goodhew

Doctor of Philosophy

Faculty of Health

University of Technology Sydney

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CERTIFICATE OF ORIGINAL AUTHORSHIP

I, Mark Goodhew declare that this thesis, is submitted in fulfilment of the requirements for the award of Doctor of Philosophy, in the Faculty of Health at the University of Technology Sydney.

This thesis is wholly my own work unless otherwise reference or acknowledged. In addition, I certify that all information sources and literature used are indicated in the thesis.

This document has not been submitted for qualifications at any other academic institution.

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Style notes

‘Single quotation marks’ without italics indicate colloquial phrases used to illustrate a point.

“Double quotation marks” without italics indicate quotations from published material that are cited as such.

‘Single quotation marks’* with *italics indicate phrases and comments by study participants that were heard in the interviews and CAG meetings and are therefore not attributed to particular people.

“Double quotation marks”* with *italics are verbatim quotes, phrases or words from individual participants (consumers and staff members) taken from the satisfaction surveys, my journal, meeting minutes or transcripts of recorded structured interviews or CAG meetings.

Glossary of terms

Consumer refers to a person that uses a health service.

Consumer participation is when a consumer is involved in the planning, delivery or evaluation of health care service delivery.

Provider/Staff member is an individual that provides health care delivery.

Substance dependence is when an individual is physically or psychologically dependent on a psychoactive drug or substance.

Supervised Injecting Facilities are services where people who inject drugs can legally inject under the supervision of professionals to reduce the harms associated with injecting drug use.

Participatory Action Research is a methodology that uses action research cycles to empower marginalised people.

Harm reduction concentrates on practical methods and ideas that can reduce the harms that are associated with drug use.

Abbreviations

AA	Alcoholics Anonymous
AIVL	Australian Injecting & Illicit Drug Users League
AIHW	Australian Institute of Health and Welfare
CAG	Consumer Action Group
HEO	health education officer
MSIC	Uniting Sydney Medically Supervised Injecting Centre
NA	Narcotics Anonymous
NHMRC	National Health and Medical Research Council
NSP	Needle and Syringe Program
NSW	New South Wales
NUAA	NSW Users and AIDS Association
NZ	New Zealand
PAR	participatory action research
PWID	People who inject drugs
SIF	supervised injecting facility
UK	United Kingdom
US	United States
WHO	World Health Organization

Table of Contents

List of figures

List of tables

Abstract

Consumer participation in health care refers to consumer involvement in decisions regarding the planning, delivery and evaluation of services. Consumer participation has been occurring in drug treatment services for over a decade, but progress has been slow due to poor organisational commitment, negative attitudes and power imbalances between consumers and providers. There are no reported consumer participation studies in harm reduction settings. This study investigated how the process of forming a consumer action group (CAG) influenced consumer participation at the Uniting Sydney Medically Supervised Injecting Centre (MSIC), a service designed to reduce the negative impacts of injecting drug use.

The aim of this study was to investigate how the process of forming a consumer group influenced consumer participation at MSIC. A participatory action research method was employed. The first stage investigated current levels of consumer participation at MSIC and motivation to form a CAG. Data for this stage included a consumer satisfaction survey (n=100), a staff brainstorming exercise (n=36) and structured interviews with consumers (n=12) and providers (n=7). In the second stage, MSIC consumers (n=11) and staff (n=5) developed a CAG. The third stage involved the implementation of the CAG's goals to enhance consumer participation. The fourth stage comprised an evaluation using a consumer satisfaction survey (n=100) and structured interviews with CAG members (n=13) and MSIC staff (n=10), and the process of the author's withdrawal from the study.

There were considerable challenges in establishing a CAG. These included: consumers' marginalised lifestyles, MSIC's biomedical model and negative attitudes of staff. Despite these constraints, there was active interest in developing the CAG. The group successfully implemented strategies to enhance MSIC's consumer participation. The consumer CAG members reported that the group helped them to improve their relationships with each other and staff, reduce drug use, address health problems and consider employment in the drug treatment services. A key factor that facilitated the group's success was the support the consumer members received from MSIC staff.

In line with previous research findings from drug treatment services, this study revealed that consumers' drug use and lifestyles can constrain consumer participation. However, the results also demonstrated that these factors were mediated by the staff's

efforts to focus on the consumers' strengths. Participation not only empowered consumers, but also increased their social capital and prompted them to make positive lifestyle changes. Overall, this study provides evidence that highly marginalised consumers can successfully contribute to service delivery when a strength-based approach is adopted.