

Auto-ethnography in Public Policy Advocacy

Louise Sinden-Carroll

Auto-ethnography in Public Policy Advocacy

Theory, Policy and Practice



Springer

Louise Sinden-Carroll
NGO Services Limited
Auckland, New Zealand

ISBN 978-981-13-1321-9 ISBN 978-981-13-1322-6 (eBook)
<https://doi.org/10.1007/978-981-13-1322-6>

Library of Congress Control Number: 2018948607

© Springer Nature Singapore Pte Ltd. 2019

This work is subject to copyright. All rights are reserved by the Publisher, whether the whole or part of the material is concerned, specifically the rights of translation, reprinting, reuse of illustrations, recitation, broadcasting, reproduction on microfilms or in any other physical way, and transmission or information storage and retrieval, electronic adaptation, computer software, or by similar or dissimilar methodology now known or hereafter developed.

The use of general descriptive names, registered names, trademarks, service marks, etc. in this publication does not imply, even in the absence of a specific statement, that such names are exempt from the relevant protective laws and regulations and therefore free for general use.

The publisher, the authors and the editors are safe to assume that the advice and information in this book are believed to be true and accurate at the date of publication. Neither the publisher nor the authors or the editors give a warranty, express or implied, with respect to the material contained herein or for any errors or omissions that may have been made. The publisher remains neutral with regard to jurisdictional claims in published maps and institutional affiliations.

This Springer imprint is published by the registered company Springer Nature Singapore Pte Ltd. The registered company address is: 152 Beach Road, #21-01/04 Gateway East, Singapore 189721, Singapore

Foreword

Walking the talk requires understanding,
empathy, transparency and courage.

The protection of those who are the most marginalized is the focus of this transformative research, namely prisoners with hearing loss. This research reflects a personal journey to address a hidden, but significant, social justice issue by a caring advocate who herself has hearing loss and can empathize with those who need services to enable them to actively participate and achieve their capabilities.

By applying Nussbaum's (2011) capabilities approach to the situation of prisoners with hearing loss, we are able to make a case for a life worth living by providing hearing loss screening for prisoner's and support services to enable them to realize their potential.

In addition, a democracy such as NZ is held up as an example, but for democracy to evolve it needs to be continuously monitored and developed to ensure the rights of all are taken into account, including those who are incarcerated. Many prisoners throughout history have had something worthwhile to say about the society and the way that their problems are represented. Democracy requires representation, accountability, the ability to sustain it through participation and the courage to listen to and believe that people who are marginalized should be heard.

Adelaide, South Australia
May 2018

Assoc. Prof. Janet McIntyre
Flinders University, South Australia
Hon Professor, University of South Africa
Adjunct Professor, University of Indonesia

Preface

This work is dedicated to my husband John and our three marvellous, outrageously fun, grown-up children and our wonderful grand-daughter.

It is also dedicated to the four doctors who helped beyond measure to ensure we remained a whole family: Dr. Hilary Blacklock, Dr. Lloyd Cairns (deceased), Dr. Rob Stewart and Dr. Andy Veale and to Dr. Clair Francomano who put the puzzle together and identified the syndrome affecting generations of our family.

It is important to pay homage to those who have walked beside us including Carol and Mike, Tom and Viv, Linda and Wayne, Paul, Karen and Edward and Marilyn and Errol.

I was raised on the maxim that, when all else fails, we have courage. In the midst of weaving my way through wicked policy issues across a range of social policy areas, I have had two constant voices of reason who have been remarkable in their wisdom and courageous in their foresight, one being my husband John and the other Associate Professor Janet McIntyre from Flinders University. Aro hanui.

Auckland, New Zealand

Louise Sinden-Carroll

Contents

1	Understanding Complex Social Environments	1
1.1	Talking the Walk: The Problems	1
1.1.1	Blood Product Safety Advocacy	1
1.1.2	NZ Crimes Act Review	2
1.1.3	Captioning for Accessibility to Broadcast Media	3
1.1.4	Prisoners with Hearing Loss	4
1.2	Walking the Talk: The Solution	5
1.3	Aiming High	5
1.3.1	Mixed Researcher Roles	5
1.3.2	Hearing Loss Rates in Prison Populations	6
1.3.3	Bowers' Report	6
1.4	Research Rationale	8
1.5	Research Design and Approach	8
1.6	Contextual Environment—New Zealand Prison Population	10
1.7	Area of Concern: Prisoners with Hearing Loss	12
1.8	Policy Makers Response	14
	References	15
2	United Nations Convention on the Rights of Persons with Disabilities: Social Cooperation and Human Dignity	17
2.1	Chapter Overview	17
2.2	Creating Capabilities	18
2.2.1	The Human Capabilities of Prisoners with Hearing Loss	18
2.2.2	The Human Capabilities of Children with Hearing Loss	28
2.2.3	Does the Social Contract Apply to Children Who Have Hearing Loss?	29
2.3	Marginalization of Prisoners with Hearing Loss	31

2.4	Social Contract Theory	35
2.4.1	Social Contract Theory: Application with People Who Have Disabilities	38
2.5	The Systems Approach	43
2.6	Critical Systems Thinking	45
2.7	Critical Systems Implementation Through Total Systems Intervention	52
2.8	Sector Review	56
2.9	Act Reviews	58
2.9.1	Accident Compensation Corporation Act (ACC Act)	58
2.9.2	Corrections Act 2005 (Parliamentary Counsel Office, 2014a)	59
2.9.3	Corrections Regulations 2005 (Parliamentary Counsel Office, 2014b)	60
2.9.4	Crimes Act 1961 (Parliamentary Counsel Office, 2015)	62
2.9.5	Electoral Act 1993 (Parliamentary Counsel Office, 1993)	62
2.9.6	Health and Disability Commissioner Act 1994 (Health and Disability Commissioner, 2009)	64
2.9.7	New Zealand Sign Language 2006 Act Access to New Zealand Sign Language Interpreters	65
2.10	United Nations Conventions and Charters Review	67
2.10.1	The United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006)	68
2.10.2	Application of the CRPD with Prisoners Who Have Hearing Loss	69
	References	70
3	Research Design and Methods: Change for Good	75
3.1	Multi-method Qualitative Research	75
3.2	Auto-ethnography: Who Holds the Knowledge and Power?	76
3.3	Ethnography (Fetterman, 2010)	81
3.4	Research Design	82
3.5	Participatory Action Research	82
3.6	Auto-ethnographic Advocacy	85
3.6.1	Human Capabilities Approach	85
3.6.2	Auto-ethnographic Advocacy: IgG Deficiency and International Advocacy	85
3.6.3	Auto-ethnographic Advocacy: Paediatric Sleep Apnoea & International Advocacy	85
3.6.4	Ethnographic Blood Safety Advocacy	86

3.6.5	Auto-ethnographic Advocacy: Blood Products	87
3.6.6	Ethnography: Carer Respite	89
3.6.7	Auto-ethnography on Learning, Lobbying and Shaping Policy in New Zealand Through the School of Lived Experience	91
3.6.8	Auto-ethnographic Reflection on Shaping Policy Internationally	93
3.6.9	Auto-ethnography on Lobbying	93
3.7	Fetterman’s Ethnography Applied to the Issue of Prisoners with Hearing Loss in New Zealand Prisons	94
3.7.1	Fetterman’s Prenatal Care: The Problem and Considerations (Fetterman, 2010)	94
3.7.2	Fetterman’s Gestation and Birth: The Proposal (Fetterman, 2010)	96
3.7.3	Fetterman’s Ethnographic Mid-Wiving: External Matters (Fetterman, 2010)	101
3.7.4	Fetterman’s Ethnographic Childhood: Field Work Preparatory Stage (Fetterman, 2010)	102
3.7.5	Fetterman’s Ethnographic Adolescent or Adult: Fieldwork (Fetterman, 2010)	102
3.7.6	Fetterman’s Ethnographic Retirement and Last Rites (Fetterman, 2010, p. 149)	104
3.7.7	Ethnographic Life-Cycle Disruption	105
3.7.8	Gestation and Birth Stage Revisited	105
3.7.9	Adolescent or Adult Stage Revisited	107
3.7.10	Retirement and Last Rites Revisited	108
3.8	Participatory Action Research	110
	References	114
4	Hearing Loss in Prisoners Policy Challenges	115
4.1	Statistical Literature Review Findings	116
4.1.1	General Population Hearing Loss Statistics	116
4.1.2	New Zealand Prison Population Hearing Loss Statistics	116
4.2	Research Questionnaire Responses	118
4.2.1	Stage-One Prisoner Questionnaire	118
4.2.2	Stage-Two Prisoner Questionnaire	122
4.2.3	Schedule of Prisoner Hearing Health Questionnaire Responses	123
4.2.4	Summary of Prisoner Questionnaire Responses	129
4.3	Questionnaire Two: New Zealand Department of Corrections	141

4.4	Questionnaire Three: New Zealand Ministry of Health	142
4.5	Policy Implications	144
	References	146
5	Diverse Application of Auto-ethnography	147
5.1	Summing up	149
5.2	Policy Design	149
5.2.1	Lack of Mandatory Hearing Testing	150
5.2.2	Ineligibility of Prisoners to Gain Funding from the Ministry of Health Hearing Aid Funding Scheme	150
5.2.3	Need for Prisoners to Have Auditory Processing Disorder Screening	156
5.2.4	Captioning to Ensure Access to Justice	157
5.2.5	Hearing Screening of the 17% of Children Who Have Parents as Inmates or Serving a Community Sentence	159
5.3	Policy and Governance Recommendations	159
5.3.1	Democratic Process Marginalization	161
5.3.2	The Need for the Hard of Hearing Advocacy to Be Heard	161
5.3.3	A Prisoner Has a Right to Access Justice	162
5.3.4	Being Marginalized	162
	References	166
6	Further Applications of Auto-ethnographic Research Models	169
6.1	Summing up	169
6.2	Recommendations	171
6.3	Conclusion	172
	References	174
	Appendix A: Correspondence to Minister and Deputy Minister for Corrections—Template, Also Sent to Minister for Disability Issues	175
	Appendix B: Official Information Act Response from the Ministry of Health	179
	Glossary of Terms	183
	Bibliography	185

List of Figures

Fig. 3.1	Research design: Stage One	83
Fig. 3.2	Research design: Stage Two	84
Fig. 4.1	Ethnicities of 100 prisoners screened for hearing loss	139

List of Tables

Table 1.1	International rates of imprisonment (2016).....	10
Table 1.2	New Zealand prisoner ethnicities	10
Table 1.3	Number of prisoners in each location by status (as at 31 March 2017)	13
Table 2.1	Eligibility criteria for receiving NZ Community Service Card.	61
Table 3.1	Questionnaire One: prisoners with hearing loss	97
Table 3.2	Section Two: Prisoner Hearing Loss Questionnaire	98
Table 3.3	Section Three: Prisoner Hearing Loss Questionnaire	99
Table 3.4	Questionnaire Three: New Zealand Department of Corrections.	100
Table 3.5	Questionnaire Four: New Zealand Ministry of Health	101
Table 3.6	Ethnographic research structure—Fetterman’s life-cycle model: Stage One.	112
Table 3.7	Ethnographic research structure—Fetterman’s life-cycle model: Stage Two	112
Table 3.8	Template of prisoner hearing health questionnaire, reproduced with kind permission from Life Unlimited, Hearing Services	113
Table 4.1	2001/2002 New Zealand Census Survey hearing loss questions.	120
Table 4.2	Category: no further action.	124
Table 4.3	Category: monitor again in 12 months.	127
Table 4.4	Category: audiological referrals	130
Table 4.5	Category: General Practitioner referral	135
Table 4.6	Category: GP referral to ORL	136
Table 4.7	Number of prisoners previously hearing tested.	139
Table 4.8	Hearing loss in the family	139

Table 4.9	Prisoner reported noise exposure by category.	140
Table 4.10	Dizziness/imbalance/head injury.	140
Table 4.11	Questionnaire two: New Zealand department of Corrections health service	143
Table 4.12	Questionnaire three: New Zealand Ministry of Health questionnaire response	145
Table 5.1	Ministry of health funding	151

Introduction

The history of applying auto-ethnographic advocacy began when I was parenting three children, two of whom were blood product dependent for many years, one of whom also slept on a Bi-PAP ventilator. All three are now successful adults but the journey to achieve that necessitated extensive auto-ethnographic and ethnographic evidence-based advocacy from us as their parents.

A brief retrospective review shows that an untenable risk to our first-born child forced the role of ethnographic advocate on me, initially in 1986 when HIV and HCV contamination of New Zealand blood products emerged as a risk in the infusions our daughter was receiving. This was then followed by the perceived risk of Creutzfeldt–Jakob disease (CJD) contamination which was considered, then, as unquantifiable, but which, over time, emerged as a low probability but high risk if it did occur.

In addition and running concurrently to the ethnographic advocacy blood safety work was the need to help our son who required Bi-PAP ventilator breathing support when asleep to achieve a quality of life that was being denied by those holding the purse strings in the pediatric health sector in New Zealand.

Eventually, we sold our family home and, with the assistance of some public donations, funded our son to see a consultant, well experienced in the care of children with his types of medical issues, based in the USA. From this, his correct medical care plan emerged. The ethnographic advocacy for our son and auto-ethnographic advocacy for us, as his parents, has retrospectively been proven many times over, to have been the best course of action to follow.

During this experience, I led the development of a national family support organization for families living with primary immune deficiencies, then worked with colleagues internationally and eventually became one of the early chairpersons of a global, international non-Government agency working in the field of primary immune deficiencies (IPOP).

Then, in the late 1990s when our two older children were in their adolescence, I was criminally assaulted when working in blood safety advocacy internationally and I had to rehabilitate from injuries to my auditory and visual processing capabilities. In effect, I was left with a permanent, moderate hearing loss and found

myself no longer able to effectively communicate with and had become marginalized literally in a matter of hours from the verbal language-based culture of my family and friends. This was a devastating loss.

When going through recovery from this ordeal, my husband challenged me to do something that I had always wanted to do, which led to me completing a master's degree in Public Management. Following on from that, I was appointed as the General Manager (2009) and then (2010) Chief Executive Officer (CEO) of The National Foundation for the Deaf (the Foundation) which is a national peak body of ten New Zealand organizations working in the quality of sound, deaf and hard of hearing non-profit sector.

Then, in 2012, I was appointed, through a global recruitment and interview process, as the Human Rights Officer for the International Federation of Hard of Hearing People (IFHOH) and in 2014 elected to the IFHOH Board as Board Member-at-Large with Human Rights responsibilities and in 2016 as their General Secretary.

This, then, has been the quite remarkable advocacy path that led to my auto-ethnographic Ph.D. research as done in regard to hearing loss in the New Zealand prison population, through Flinders University, South Australia.