IS ACCESS AND EQUITY EXTENDED TO NEW ZEALAND PRISONERS WHO ARE HARD OF HEARING?

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DOCTOR OF PHILOSOPHY

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LIST OF ACRONYMS

ACC	Accident Compensation Corporation
APD	Auditory Processing Disorder
BORA	Bill of Rights Act (1990)
Captioning	sub-titling on broadcast media
CEO	Chief Executive Officer
Corrections	Department of Corrections
CRPD	Convention on the Rights for People with Disabilities
CST	Critical Systems Thinking
deaf/Hard of Hearing	People who support the use of technology to hear
Deaf	People who use sign language to communicate
FM	Frequency Modulation
CJD	Creutzfeldt–Jakob Disease
Foundation	The National Foundation for the Deaf
GP	General Practitioner (Community-based family doctor)
GST	Goods and Service Tax
HAFS	Hearing Aid Funding Scheme
HASS	Hearing Aid Subsidy Scheme
HEDS	Hypermobile Ehlers Danlos Syndrome
IDA	International Disability Alliance
IFHOH	International Federation of Hard of Hearing people
IPOPI	International Patient Organisation for Primary Immunodeficiencies
Kaumatua	Maori Elder
KIDS	Kids Foundation for Children with Primary Immunological disorders
LUHS	Life Unlimited Hearing Services
MECF	Mt. Eden Corrections Facility
MOI	Prisoner health questionnaire
NIHL	Noise Induced Hearing Loss
NZAS	New Zealand Audiological Society
NZSL	New Zealand Sign Language
ODI	Office of Disability Issues
ORL	Otolaryngology (ENT Surgeon)
PAR	Participatory Action Research
PARS	Prisoner Aid and Rehabilitation Society
Project Hiedi	Project for hearing identification and early diagnosis
Serco	Serco Private Prisons
TSI	Total System Intervention
UN	United Nations
UN UPR	United Nations Universal Periodic Review
UNESCO	United Nations Educational, Scientific and Cultural Organisation
VA	Veterans Affairs
WHO	World Health Organisation

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ABSTRACT

This policy and public administration thesis aims to explore the extent to which access and equity in services is extended to New Zealand prisoners who are hard of hearing. The thesis makes a contribution to policy by determining to what extent the capabilities of prisoners with hearing loss have been addressed since the 1981 Bowers report. The latter report highlighted that all Maori and 84% of other New Zealanders tested in prison had abnormal ears and/or hearing loss. The thesis explores to what extent her recommendations to address testing and preventing hearing loss have been implemented and makes recommendations on the need to enhance social inclusion and social justice opportunities through better testing protocols in prison. Thus, this thesis details gaps in the existing services and in theoretical terms makes an original contribution to the policy literature by applying the capabilities approach to prisoners in New Zealand correctional services.

CANDIDATE DECLARATION

I certify that the thesis entitled:

IS ACCESS AND EQUITY EXTENDED TO NEW ZEALND

PRISONERS WHO ARE HARD OF HEARING?

This thesis is the result of my own work and that where reference is made to the work of others, due acknowledgment is given.

I certify that this thesis does not incorporate without acknowledgment any material previously submitted for a degree or diploma in any university; and that to the best of my knowledge and belief it does not contain any material previously published or written by another person except where due reference is made in the text.

FULL NAME: LOUISE MARION CARROLL

SIGNATURE: 

DATE: 24 December 2015

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DEDICATIONS

To John, Katie, Jade, Aroha and

In memory of Dom

Kia Kaha

Stay strong –

when all else is lost

we have courage

(PD Sinden, 1975)

1

HUMAN CAPABILITIES OF PRISONERS WITH HEARING LOSS

1.1 Statement of the Problem

> "In the most general sense, all oppressed people suffer some inhibition of their capability to develop and exercise their capacities and express their needs, thoughts and feelings" (Young, 1990, p. 4).

Health research indicates that the three most important markers of psychosocial stress in modern society are low social status, lack of friends, and stress in early life (Wilkinson, 2010, p. 39).

Accordingly, if the social construct which allows the development of the prison social structure reflects the construct from which society in general has evolved, then it is very likely that prisoners with hearing loss will be of a lower social status, will frequently struggle to understand their environment and make sense of human relationships and will be unable to realise many of their capabilities.

1.2 Researcher Introduction

As a survivor of a significant injury that occurred when working internationally at the age of 39, which caused permanent hearing, visual and balance disabilities, the writer contributes her lived experiences to this research in addition to the skills of being a researcher, advocate and as well, CEO of a non-profit, peak body, working in the disability sector in New Zealand.

Whilst recognising that asking sensitive questions can cause emotional responses ranging from uncertainty to anger, or even joy and hope from those responding, researchers have "the freedom of not knowing [the answers, and can experience] confusion, uncertainty and anxiety" (Wadsworth, 2010, p. 41). But, the writer is also personally able to identify with the respondents as she shares some of their experiences of being marginalised because of her disabilities.

In addition to being an individual who has 'walked the talk' in regards to disabilities, in late 2009 the writer was firstly appointed as the General Manager and then (2010) Chief Executive Officer (CEO) of The National Foundation for the Deaf (the Foundation), a

national peak body for organisations working in the quality of sound, deaf and hard of hearing non-profit sector in New Zealand. Then, in 2013, the writer 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.

1.3 Research Aims

The logical path for this research to follow is to identify the extent of the marginalization of prisoners in New Zealand prisons who are hard of hearing by asking the New Zealand Department of Corrections (Corrections) to what extent the disability of hearing loss is identified and accommodated within the prison population. Then, identify what services are provided by the Ministry of Health to prisoners with hearing loss so as to enhance their human capabilities through rehabilitation. Thus, the area of concern for this research is to find out to what extent the rights of prisoners with hearing loss are being addressed and whether their capabilities are recognised and addressed through the prison system.

In the United Kingdom it is reported that in the general population, for every six people, one person has some type of hearing loss (Action on Hearing Loss, 2010) and in the United States for every ten people, one person has some type of hearing loss (Academy of Audiology, 2008). Whereas, in prison populations both nationally and internationally, one in three prisoners are reported as having some type of hearing loss.

In New Zealand both Maori and Pacific Island people are significantly over-represented in prison populations whereas Asians and Europeans are under-represented. This indicates that New Zealand prisons have a higher rate of marginalised, vulnerable and less powerful citizens suffering with social inequality with a resultant lack of social status who are failing to comply with or are unable to meet the requirements of the New Zealand legal system.

This research evolved with the aim of determining if access and equity is extended to a marginalized group, identified as a specific New Zealand prison population subset, namely prisoners with hearing loss and to what extent the New Zealand Government has responded to the Bowers Report policy recommendations concerning the way in which New Zealand prisoners with hearing loss have their audiological tertiary health and rehabilitation needs met (Bowers, 1981, p. 17).

Much is known about being profoundly deaf but little research has been done to understand how having partial hearing loss impacts on life opportunities. Hearing loss is

reputed to be a risk factor for anti-social and possibly criminal behaviours (Bowers, 1981, p. 17). But these types of unproven beliefs perpetuate discrimination and stigmatization against a group of people who have one point of commonality, namely a specific type of disability which is, all too frequently, negatively viewed by society.

In 2010, whilst archiving old documents at the Foundation the writer came across the Bowers Report (Bowers, 1981) in which the author identified the occurrence rates and the plight of prisoners with hearing loss in New Zealand prisons and serving community sentences. The results published in the Bowers Report were disturbing because of the writer's empathetic response to people struggling with hearing loss as she is fully cognisant of the potential for a concomitant loss of capabilities and life opportunities that this disability can cause.

As a result of reading this report the writer raised the subject of prisoners with hearing loss with the Foundation's Council Chair Professor Peter Thorne. His response indicated that he believed little had changed for this marginalised group.

In effect, the Bowers Report (1981) appears to have had minimal impact. Prisoners with hearing loss remain unidentified and policy has not been developed by either Corrections or the New Zealand Ministry of Health to address their disability rehabilitation needs. It quickly became apparent there is an on-going significant health and disability issue in New Zealand prisons that is being mostly ignored by the Government agencies responsible for prisoner wellbeing and societal re-integration. But though there has been neglect of prisoners with hearing loss, this does not exonerate Corrections or Serco as they know a posteriori from Bowers Report (1981) and from the 2005 Prisoner Health Survey done by the New Zealand Ministry of Health that they have a significant issue requiring urgent attention.

1.4 Research Rationale

Prisoners with hearing loss experience multiple ways of being marginalised including physically, geographically, institutionally, attitudinally and democratically, all of which will be examined in-depth further on. Accordingly, the rationale under-scoring this research is how to identify their unaddressed needs and recognise their capabilities as human beings.

Also, in chapter two, the following questions will be examined in-depth: is there an expectation that the State will provide reasonable disability accommodation and rehabilitation to enable prisoners with hearing loss to achieve equality with hearing abled

prisoners; will prisoners with hearing loss remain disempowered, vulnerable and at risk of a continuing low social status and poor life outcomes if the State does not support the prisoners.

1.5 Research Design and Approach

The research uses a mixed method design comprising ethnography, auto-ethnography, case study and critical reflection on a survey. The area of concern is identified first and then the research approaches were combined at appropriate intervals to address it. The design also offers a pathway to research the subjective experience and objective findings through the participatory action research model.

As the writer has hearing loss, to accommodate this disability, the preferred model of information gathering is in the written format using closed (yes/no) questions for prisoners to answer and open ended questions in a questionnaire format for Corrections, Ministry of Health and Prisoner Aid and Rehabilitation (PARS) staff to respond to. Accordingly, the research tools will be a series of questionnaires that will be applied in combination with establishing key player relationships with individuals who may be able to support and promote positive change.

The additional benefits of using questionnaires is that they can be designed to meet the cultural needs and reading and comprehension skills level of those being asked to provide the information though misrepresentations and misinterpretations are a recognised risk in this model of research. This is because the questionnaire respondent may respond idealistically or as they believe the researcher wants them to answer (Fetterman, 2010, p. 56). Also this section uses the process to reflect on the process.

Questionnaire one was designed to capture the hearing health histories of fifty male prisoners. Prisoners were asked to complete the Questionnaire in a one to one meeting with an interviewer from the non-government organisation PARS http://www.pars.co.nz 2015) when they are doing their pre-release interview.

Questionnaire two was designed to survey Corrections health staff about the detection of hearing loss in prisoners and the provision of rehabilitation services. The third questionnaire was designed to solicit policy information from the Ministry of Health funding contractors responsible for the delivery of hearing health programmes and questionnaire four will be designed to elicit information from the non-government PARS prisoner interviewers on the prisoner response to questionnaire one.

Also, as will be reported in chapter five, programmes implemented by the New Zealand Government for the diagnosis and treatment of ear disease in children will be identified and perceived gaps as identified by hearing loss sector advocates will be defined.

Reviews of the United Nations Convention on the Rights of Persons with Disabilities CRPD (www.un.org/disabilities/convention/conventionfull.shtml) and how this is upheld and applied to this at-risk population in New Zealand will also be done in chapter two as will the probable State neglect of prisoners with hearing loss which will be examined through the lens of the human development approach of creating capabilities.

Also, in chapter 2, examination of discrimination and stigmatization in the context of identifying whether the State has a duty to provide for the powerless within the social contract will be done as will an examination of the five faces of oppression defined as the exploitation, violence, marginalization, powerlessness and cultural imperialism in chapter two.

In-depth discussion on the research design occurs in Chapter three, where the approach and methodology will be described and then the barriers and break-throughs on this complex issue are outlined. This will include a retrospective review of the extensive application of participatory action research in systems advocacy, which the writer has undertaken to address inequities in health, disability, policing and criminal justice sectors and why this type of research was the preferred model.

In chapter four, the research findings are detailed and their impact considered. Questionnaire results will then be examined, as will the strategic picture that the questionnaire results paint. Then, in chapter five, the evolving situation as policy windows open will be defined and conclusions will be detailed. As the writer is an agent for social change through public policy advocacy, chapter five will also define a strong advocacy programme. Finally, further research avenues to support the change of life journeys for many prisoners who are hard of hearing will also be explored.

Bowers (1981) identified that Maori prisoners had a high incidence of ear disease and hearing loss and that the general prison population had a higher rate of hearing loss than the non-incarcerated general population (Bowers, 1981, p. 14). She provided an evidential base of audiograms recorded from 100 hundred Maori and 100 European young male prisoners aged between 15 and 25 years of age who were on remand and volunteered to be hearing screened, the results of which proved there is an issue with hearing loss in

prisoners. Of the European prisoners 54% had hearing loss of 15dB or greater in one ear as did 83% of the Maori prisoners screened (Bowers, 1981).

Of note, 37% of the European prisoners and 60% of the Maori prisoners also had a loss of 15db or greater in their better hearing ear (Bowers, 1981, p. 7). There was also a very high rate of non-recognition of hearing loss by the prisoners screened and Bowers reported this as her most significant finding. She also believed that this was most likely one of the causal factors underscoring the outcomes of job instability and poor educational achievement earlier in life.

From Bowers' (1981) research findings and the Prisoner Health Survey (2005) it is evident that a range of prisoner's disability support and rehabilitation needs are unrecognised, their capabilities of what they are able to be and do remain unexplored and they are viewed as being of lower status and unable to participate as equal partners to the social contract.

Bowers' (1981) research established that the support and rehabilitation needs of prisoners who were hard of hearing were not being met in the 1980's and she made a number of policy recommendations.

These recommendations included the proposal that "[e]fforts to recognise and treat ear disease in children deserve the fullest support of the community" (Bowers, 1981, p. 17) and that prisons should probably include recognition and treatment of ear disease and hearing loss in their rehabilitation programmes.

Accordingly, one of the questions this research will explore is whether policy makers implemented Bowers' recommendations in full in the 1980's? If not, how are prisoners who are marginalized by hearing loss being heard or their needs for rehabilitation and societal support on reintegration being met?

To conclude this section, whilst participating in an Australasian workshop on hearing loss into the 2020's there was great interest in the ethnographic participatory action research model being applied to the analysis of government policy in regards to prisoners with hearing loss. This is because it has not been done before and the workshop participants who came from a wide range of hearing health services in Australasia believed it to be much needed and long overdue. Accordingly, the writer will be applying the participatory action research based on Fetterman's ethnographic life-cycle model in the knowledge that

thought leaders in the hard of hearing sector support this research and believe it to be appropriate to do.

In addition, underscoring the need to complete this research and publish the findings is the requirement to form a credible basis from which government agencies will be able to respond in a positive and practical way to meet the support and rehabilitation needs of prisoners with hearing loss in New Zealand.

1.6 Contextual Environment - New Zealand Prison Population

Table 1.1 indicates that New Zealand's rate of imprisonment is recorded at 185 per 100,000 citizens. This is a significantly higher rate than in Australia, which has 129 people imprisoned per 100,000 citizens.

Table 1.1. International Rates of Imprisonment (2009)

International Rates of Imprisonment (2009) per 100,000	
United States	756
Chile	305
Singapore	267
Poland	221
Malaysia	192
New Zealand	185
Czech Republic	182
Spain	160
England & Wales	153
Hungary	149
Australia	129
Canada	116
Denmark	63

(Department of Corrections, 2009)

To unpack this further, it is necessary to consider New Zealand prisoner ethnicities, as this may show that in New Zealand some people are more vulnerable, less powerful or more marginalised, such as indigenous populations.

Table 1.2. New Zealand Prisoner Ethnicities

New Zealand Prisoner Ethnicities (June 2012)		% of population (2013)
Asian/Other	3.6%	10.9%
European	33.0%	67.0%
Maori	**51.0%**	**14.0%**
Pacific Peoples	**12.0%**	**7.0%**
Unknown	0.4%	1.1%

(Department of Corrections, 2009)

New Zealand Police Force Commissioner Mike Bush reported on TV3 national news, on Saturday November 28, 2015 that the New Zealand Police Force have been influenced by an unconscious bias against Maori and that 46% of Police apprehensions are Maori, 50% of police prosecutions are against Maori; 60% of Youth Court appearances are by Maori and 50% of New Zealand prison population are Maori.

Commissioner Bush said that Police "data that was collected right from the start showed there is a disparity in the way they apply discretion. We have to acknowledge that it exists….[and] since we started having those conversations and talking about it that the dynamics has really changed and we are getting far closer to the equality that should be there" (TV3 news verbatim quote).

It is heartening to hear the New Zealand Police Force are acknowledging they have an unconscious bias and this may go some way to addressing the inequitable representation of Maori in New Zealand prisons.

Wilkinson & Pickett, (2010, p. 135) stress that discrimination is even more relevant than social inequality in determining life chances and health. Also, violent crimes such as homicides and assaults and social inequality were closely linked in 34 out of 35 American States studied and the U.N. Surveys on Crime Trends and the Operations of Criminal Justice Systems showed that international homicide rates are related to social inequality as well (Wilkinson & Pickett, 2010, p. 135).

The New Zealand Police report that crimes of dishonesty are the most prevalent nationally followed by drug abuse and antisocial behaviour, violence, property damage, property abuse, administrative crimes and then sexual abuse (Crimes in New Zealand: 1996-2005, 2006).

The cross cultural context of policing needs to be addressed at this point because when citizens of Maori descent commit crimes against the person or property this can cause culturally required challenges known as ‘utu’ (Ministry of Justice, 2013b) and the need for the restoration of an equal power balance may present.

When the writer was employed by the fledgling Waitakere District Court Restorative Justice Programme in 2002, it was evident that not all victims with power loss would choose to participate in the restorative justice programme, instead deciding to mete out their own form of justice. This could underscore and partially explain the increased rate of prison sentences given to Maori male prisoners.

These findings fit with the notion that the Commonwealth legal system does not merge well with the model of Maori cultural law/lore in which the concept of utu applies (Ministry of Justice, 2013b) to ensure the maintenance of power balance in relationships by the seeking of revenge and the reciprocation of kind deeds.

In recognition of this, there have been some quite successful attempts to ensure the concept of Utu is integrated into the New Zealand legal system through the restorative justice programme (Ministry of Justice, 2013a) administered nation-wide by the Ministry of Justice.

This information is vital for policy developers as strong emphasis needs to be on including appropriate cultural designs in all programmes aimed at upholding social status and preventing marginalisation and reducing recidivism.

Table 1.3. Sentences and Orders by Location

Sentences and orders by area* (as at 31 December 2012)			
	Sentences	**Orders**	**Total**
Auckland	3,056	646	3,702
Bay of Plenty	1,686	459	2,145
Christchurch	2,960	752	3,712
Sentences and orders by area* (as at 31 December 2012)			
East Coast	1,848	553	2,401
Manukau	4,701	823	5,524
Nelson & Marlborough & West Coast	1,245	220	1,465
Otago	1,022	314	1,336
Southland Central	901	282	1,183
Taitokerau	2,247	462	2,709
Taranaki	1,003	350	1,353
Taupo & Rotorua	1,720	414	2,134
Waikato	2,648	670	3,318
Wairarapa Manawatu	1,670	352	2,022
Waitemata	2,902	442	3,344
Wellington	2,281	497	2,778
Total	**31,890**	**7,236**	**39,126**

(Corrections Department of New Zealand, 2009)

The primary mandate of the Department of Corrections is to ensure public safety which is achieved by prisoners serving their sentences and being rehabilitated. As well, they have set the target of a 25% reduction in recidivism by 2017.

Approximately 45,000 community sentences and 19,000 sentences involving imprisonment are bestowed by the New Zealand judiciary each year, at a cost to New Zealand tax-payers of $2.8 billion dollars. One community sentence costs the tax payer $9,400 per annum and one full year in prison $94,000 (Lynds, 2013).

1.7 Area of Concern: Prisoners with Hearing Loss

Prisoners with hearing loss do not have a voice and are often marginalized in multiple ways, firstly through having a communication disorder and secondly as a result of being socially and geographically isolated through incarceration. Thirdly, they are most likely attitudinally isolated, through “cynicism and [feeling] meaningless [which] are by-products of perceived or real marginalization” (McIntyre, 2002, p. 11) and fourthly due to the fact

that in 2010 an amendment was made to the Electoral Act 1993 and New Zealand prisoners convicted and currently incarcerated since 2010 are now denied their democratic right to vote. This will be further examined in the Act reviews in chapter two.

[redacted]

This paragraph has been removed due to confidentiality.

Furthermore, if a prisoner is not actively identified as having hearing loss, they will be unable to access the tools and services they require, to ensure they have the opportunity to establish functional relationships and gain meaningful employment when released. Though this may appear trivial when compared to the greater impact on access caused by incarceration, it has been reported that hearing loss, unless actively managed, causes significant social isolation; loss of career opportunities and depression (The Australian Senate, 2010, p. 36).

Hearing difficulty was the most frequent sensory disability self-reported by New Zealand prisoners in 2005 (Ministry of Health, 2006, p. 13). But, how will a prisoner who is disenfranchised from society through hearing loss; incarcerated with a loss of democratic rights, struggling to understand the prison system and probably feeling hopeless and unable to contribute in a meaningful way to the prison community and wider society be able to access rehabilitation?

Unless the State provides reasonable disability accommodation to enable prisoners with hearing loss to achieve equality with hearing abled prisoners, they will remain disempowered, vulnerable and at risk of a continuing low social status and poor life outcomes. There is also the question on what is the State's responsibility or duty to provide such rehabilitation; in fact, do they have an obligation through social contract to do so? These questions will also be examined further in chapter two.

1.8 Policy Makers Response to this Thesis

So often, rather than being the solution, planning is the problem because some, but not all, bureaucrats who have done the planning impose their solutions. Their policy plans are developed in isolation and without co-determination of policy by those who are involved and those who will be most affected by policy decisions (Urlich,1996/2014).

When considering external parties' personal views and vested interests it is vital to also consider the personal biases of the writer. Accordingly, as an ethnographer it is important to question and define through the writings who I am and "...anticipate how the public and policy makers will receive, distort and misread [the] data [findings and recommendations]" (Fine, Weisss, Weseen, & Wong, 2000, p. 127).

This is because "[t]he ethnographers task is not only to collect information from the emic, or insider's, perspective but also to make sense of all the data from an etic, or external, social scientific perspective" (Fetterman, 2010, p. 22).

Policy responses in the areas of resource allocation to the hearing loss sector by both Corrections and the Ministry of Health will be examined. Also, social justice including governance and democratic rights will be considered because of the retrenchment of prisoner rights to vote and participate in democracy, which increases their significant marginalisation even further.

As an advocate for over twenty-five years duration in areas of wicked social problems (Rittel & Webber, 1973, pp. 160-167), the writer is no stranger to being vilified and ostracized when trail blazing to achieve social change. Even though repeatedly experiencing the impact of being "isolated, targeted, derided and demeaned" (Wadsworth, 2010, p. 154) the writer has not quietly slunk away, instead, persisting in giving the message that consumers want heard.

[redacted] This paragraph has been removed due to confidentiality.

Also, it is not uncommon for community organisations, perceived as having the potential to cause trouble for government especially at times leading up to general elections, to be kept busy on non-essential work believed to be non-threatening to the status quo. This tactic can reduce the impact of their advocacy work as community organisations often have limited resources and capacity, which is being diverted on projects that the government deems politically safe.

In addition, having done many years of advocacy work for the disenfranchised, the writer has frequently observed buzzing blooming confusion (Wadsworth, 2010, p. 41) which is seen when systems are under threat of change. Accordingly, even though there may be a high degree of public sympathy towards the cultural linguistic Deaf and the Hard of Hearing technology using sectors, the dominant political philosophy and fiscal environment

prevalent at the time of publication, as well as the receptiveness of service providers to implement any recommendations, will mandate the impact of such recommendations.

2

LITERATURE REVIEW: CAN SOCIAL COOPERATION FOSTER HUMAN DIGNITY?

2.1 Chapter Overview

Systemic intervention requiring a methodological mixture of quantitative and qualitative and participatory action research and autoethnographic work will be done to identify if there is a need for advocacy endeavours to enable prisoners with hearing loss in New Zealand prisons to achieve equity with hearing able prisoners.

In addition and as outlined previously in chapter one, reviews of both literature and public media sources will be presented as they apply to the capabilities and rights of prisoners with hearing loss in this chapter. Then, reviews of the cultural-linguistic Deaf culture and the Hard of Hearing technology-using sector in New Zealand will be offered which will outline the external environment this research is situated within.

After that, consideration of the State neglect of prisoners who are hard of hearing will be done through the lens of the human development approach of creating capabilities. Also, examination of discrimination and stigmatization by considering Iris Youngs' (1990, p's 39-63) Five Faces of Oppression defined as being exploitation, violence, marginalization, powerlessness and cultural imperialism in the context of identifying whether the State has a duty to provide for the powerless within the social contract will be done. As well, a study of the relevant laws and United Nations conventions to identify if they are mandated in New Zealand law, or not and how they are upheld and applied to this at-risk population in New Zealand will also be offered.

Then, in Chapter 5, normative policy design, the theory of which will be described further in Chapter 3, will be applied to offer a suggested path forward to address the issues this research may uncover.

2.2 Creating Capabilities

Nussbaum (2006, p. 202) proposes that social cooperation can occur with the purpose of fostering the well-being and dignity of all people and that the social contract does not go far enough in this regard. This is because it does not protect those who do not have citizenship rights and who do not vote because they are too young, too frail or, are not

permitted to vote. In line with this notion, Nussbaum (2006, p. 76) described the Human Capabilities Approach which includes a list of ten human capabilities, as “a basic principle of each person as [an] end, in their own right”. She stated that the ten minimum core social entitlements, called capabilities (2006, p. 75) applied for all people, not only citizens, no matter their point of origin or status in society.

Capabilities are defined as our innate abilities and the opportunities or freedom developed by these personal abilities being combined with the social and political environment (Nussbaum, 2011, p. 20).

Nussbaum considers each person to be an end in themselves and to also need fulfillment of ten components or capabilities to be a fully functioning person. By promoting the ten capabilities she has detailed in the Human Capabilities Approach, it could prima facie appear that she is applying the reductionist approach (Flood, 2010, p. 133). This is because she defines that the Human Capabilities Approach has ten individual components, thus reducing a human being into ten functional components.

However, the ten capabilities in fact reflect the whole person and as such, it is evident that people are unable to be fully comprehended from their constituent parts. This is because by applying the Human Capabilities Approach the theory of emergence applies which rapidly shows that a person is greater than the sum of their individual capabilities. Accordingly, it is necessary to build up the whole picture of a prisoner with hearing loss, rather than break them down into their constituent parts, in order to gain meaningful understanding and greater knowledge about their needs.

2.2.1 The Human Capabilities of Prisoners with Hearing Loss

The Human Capabilities Approach will now be studied on a component-by-component basis, analyzing each for cause and effect, offering a global view of how prisoners with hearing loss are having their individual human capabilities met in their current environment.

In doing so, the writer will then be offering a critical systemic view of the inter-related factors that need to be taken into account when understanding how and why prisoners with hearing loss are neglected and the policy and administration environment of this area of concern. The aim is to provide greater understanding of the issue through considering it in terms of social, cultural, political and economic dimensions that shape the life chances and the capabilities of prisoners. It is also vital to understand that the synergy or

emergence of a whole organism, human or otherwise, is greater than the sum of its parts (Flood, 2010, p. 133), which this writer believes very much relates to prisoners with hearing loss.

This is because some of their capabilities are recognised in their own right and in addition the very same capability can influence and add strength as a cross-over right thereby supporting other capabilities e.g. capability # 5 emotions is a good example of this as it also impacts and strengthens a range of other capabilities. This also reflects the impact of lawful relationships in which prisoners with hearing loss knowingly manipulate their environments to accommodate and lessen the impact of their inability to fully hear, thus minimizing it's impact and increasing the sum of their capabilities.

The 10 human capabilities as defined by Nussbaum (2006, p. 76), in the Human Capabilities Approach will now be examined as to how they apply to prisoners with hearing loss or whether in fact they cannot apply to this subgroup because of circumstances beyond the prisoners control, such as the prevailing rules and regulations in the prison.

Sensibly, Nussbaum identified the number one capability as that of "*Life: Being able to live to the end of a human life of normal length; not dying prematurely, or before one's life is so reduced as to not be worth living*" (Nussbaum, 2006, p. 76).

Hearing loss can induce an all-encompassing loss of capability, thereby impacting negatively on every aspect of a person's life. As a result, it is not uncommon for the individual who is hard of hearing to achieve a lower social status in the community due to social marginalisation and experience a higher rate of lost life opportunities than their sibling peers who are hearing abled (The Australian Senate, 2010, p. 26).

This was evidenced by the writer, when an elderly woman who has profound hearing loss attended her sibling's funeral and she chose to stand with her community support team rather than with her family during the ceremony as her family members had always treated her as less than equal.

Accordingly, when considering the life quality of a prisoner who has a significant, but undiagnosed or mismanaged hearing loss, there may well be times when they consider their life is reduced to the point of not being worth living. Increased rates of depression are associated with hearing loss (The Australian Senate, 2010, p. 36). Accordingly, the life spans of prisoners with hearing loss may well be shortened unless active interventions are taken to address the acknowledged increased risk of depressive disorders occurring in

people who are hard of hearing or deaf. First, identifying prisoners who are hard of hearing and then, ensuring they are given the support and rehabilitation they require to enable them to overcome the isolating and marginalizing effect of hearing loss and achieve integration will address at least some of this risk.

The second capability as identified by Nussbaum is that of "*Bodily Health*: *Being able to have good health, including reproductive health, to be adequately nourished; to have adequate shelter*" (Nussbaum, 2006, p. 76).

Human beings generally aspire to achieve nourishment, a roof over their head, a family to emotionally connect, reciprocate, love and grow old with.

Whilst imprisoned in New Zealand, prisoners will receive health and emotional care sufficient to achieving a level that will enable their successful reintegration at release but rarely, if ever, would it address any reproductive healthcare need that may be present at the time of sentencing unless it is life threatening.

In addition, prisoners with hearing loss are at a disadvantage because of their lower life status and when re-integrated into society some will struggle to maintain well-health, a relationship with a life partner, achieve adequate income and shelter.

The second aspect of the capability of *Bodily Health*, which is employment, will be a difficult one for some prisoners with hearing loss to realise as they may be ill-educated, and employment will be difficult to attain or if secured, to keep long-term.

Serco Private Prisons and Corrections will provide nourishment, accommodation and sufficient but not full health services for incarcerated prisoners. But when released, prisoners who have hearing loss will need full support by the New Zealand Probation Service or the NGO PARS to achieve integration and avoid the recidivist pathways. Hearing loss is a very significant barrier to achieving all that is needed to meet capability #2.

The third capability as identified by Nussbaum is that of "*Bodily Integrity: Being able to move freely from place to place; to be secure against violent assault, including sexual assault and domestic violence; having opportunities for sexual satisfaction and for choice in matters of reproduction*." (Nussbaum, 2006, p. 76).

The capability of being able to move freely from place to place is clearly one that prisoners will be unable to realize for the duration of their sentence; they are at an increased risk of both violent and sexual assaults in the prison environment and most are unlikely to achieve sexual satisfaction and achieve choice in the matters of reproduction whilst incarcerated, though there are some prisons in the United States that permit prisoners who are serving longer term sentences to meet privately with their spouses.

When a prisoner is of lower status in the prison population they are more vulnerable to abuse of all types and bullying from prisoners who are perceived to be of higher social status. Capability #3 is at high-risk of being neglected unless prison authorities actively manage the prison environment to ensure it is safe for all, especially the more vulnerable lower status prisoners, which would more than likely include those with disabilities such as hearing loss. Therefore, in the prisoner population, the third capability, of *Bodily Integrity,* can, at best, be partially implemented.

Nussbaum described the fourth capability in the Human Capabilities Approach as "*Senses, Imagination and Thought: Being able to use the senses to imagine, think, and reason – and to do these things in a "truly human" way, a way informed and cultivated by an adequate education including, but by no means limited to, literacy and basic mathematical and scientific training. Being able to use imagination and thought in connection with experiencing and producing work's and events of one's own choice, religious, literary, musical and so forth. Being able to use one's mind in ways protected by guarantees of freedom of expression with respect to both political and artistic speech, and freedom of religious exercise. Being able to have pleasurable experiences and to avoid non-beneficial pain*." (Nussbaum, 2006, p. 76).

When considering the capability of senses, thought and imagination, the first consideration is the impact that undiagnosed or mismanaged hearing loss will have on what a prisoner with hearing loss is able to achieve. Will they be able to produce or hear and enjoy music; be able to freely express their political and artistic speech and practice religion? Will they have less pleasurable experiences than their hearing peers in the prison population and will they be at risk of receiving higher rates of non-beneficial pain?

For the music component of capability four to be actualized a prisoner will need to access technology such as hearing aids or cochlear implants or they will need to see sign language singers if this is their preferred communication modality as they will not be able to realise it any other way.

Consideration is now given to if a prisoner will be able to freely express their political and artistic speech and freely practice religion. They will be unable to utilize their literary capabilities if they are not adequately supported to access learning. Nor will they be able to contribute to society by expressing their political and artistic speech and be designers of their own destinies through political participation if they are not permitted to vote in general elections.

Prisoners with hearing loss will also need to be recognised as a vulnerable group that is more at-risk of abuse and receiving non-beneficial pain and will require increased protection provided by prison authorities, ensuring they are not targeted by prison bullies. With regards to practicing religion, prisoners have ready access to the prison chaplaincy services.

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However, it would be reasonable to consider that adults, including prisoners, who had a lifetime of mild to moderate hearing loss have struggled to achieve at the same level as their hearing abled peers. This may be an important contributing factor, amongst a number of significant reasons, underscoring why so many prisoners who have hearing loss have made poor life-choices.

Capability #4 shows, once again, why it is vital to identify if a prisoner is hard of hearing as they will need appropriate support to be able to fully realise this capability.

As a person with hearing loss the writer is able to understand the challenges it will bring to prisoners who have similar communication challenges because they will find it very difficult

to realise their capabilities of senses unless **actively supported** by prison authorities and their fellow prisoners and, indeed, society as a whole, to do so.

Capabilities of imagination and thought will be realised though to what degree is unknown. A growing number of prisoners who have had their capabilities recognised by prison authorities have achieved an academic education and graduated whilst incarcerated which shows that some prison authorities do uphold the application of the prisoners' capability to imagination and thought.

By doing so, these prison authorities then overcome one of the most significant developmental impact gaps that coming from a lower social status creates, the need for knowledge that will help an individual to achieve a higher social status. Some prisoners may then be able to implement capability #4 and move from the path of recidivism to that of being creators of their own life destinies, no longer being victims of circumstances.

Next, capability #5 of the Human Capabilities Approach *Emotions* is considered. *Being able to have attachments to things and people outside ourselves; to love those who love and care for us, to grieve at their absence; in general, to love, to grieve, to experience longing, gratitude and justified anger. Not having one's emotional development blighted by fear and anxiety. (Supporting this capability means supporting forms of human association that can be shown to be crucial in their development)* (Nussbaum, 2006, pp. 76-77).

Communication underscores the emotional development and growth of all human relationships, whether achieved verbally, through captioning or subtitling, or, if preferred, by sign language.

But if a child has undiagnosed hearing loss they will be unable to establish effective communications with their parents, caregivers, siblings, peers and probably all others they have contact with too. They are at risk of failing to bond and developing attachment disorders, as they may be unable to develop healthy emotional attachments because of communication failure (Sacks, 1990).

If an adult loses their ability to effectively communicate after being a life-long verbal communicator it has been reported that a grief and loss process and depression may occur (The Australian Senate, 2010).

People living with hearing loss often experience confusion, surprise and in some circumstances fear from poor information input from their immediate environments and

confusion may occur at rapidly evolving situations, which they are unable to process because of communication failure.

Having experienced repeated challenges to capability #5 the writer cannot over emphasize the unpleasantness of such regularly occurring surprises. It is most definitely fear-inducing to be repeatedly surprised and accommodations such as an office having a glass wall instead of a visibly closed one to ensure people are able to be seen, plus positioning of the desk in the office so the persons entering the room are in the line of sight of the person with hearing loss are just some of the accommodations required to alleviate this. [redacted] This paragraph has been removed due to confidentiality.

Sacks (2000) reports of situations where people with unrecognised hearing loss were often clinically diagnosed as being "'incompetent' and were denied fundamental human rights" because they could not build appropriate human associations through communication.

Hopefully the practice of incarcerating people with hearing loss in asylums for the insane is no longer occurring. However, it is recognised that prisons are now mopping up society's vulnerable (Stanley, 2011) and the question that begs the asking is, whether the asylums have been replaced by prisons?

If a child has unidentified hearing loss or an adult develops it later in life and neither have access to support to establish or re-establish and maintain communication both groups will be unable to appropriately sustain their human emotional connections, responses and growth and the fifth capability cannot be realised.

If their hearing losses are recognised and they achieve the required rehabilitation then it is very likely that, with on-going support, capability #5 *Emotions* will be functionally possible.

Nussbaum's 6th capability is defined and described as: "*Practical Reason. Being able to form a conception of the good and to engage in critical reflection about the planning of one's life. (This entails protection for the liberty of conscience and religious observance)"*. (Nussbaum, 2006, p. 77).

Prisoners with hearing loss may be in prison because they have been unable to consistently apply sound practical reasoning and made poor decisions that have led to criminal convictions. Though Nussbaum promotes the notion that the ten capabilities are a minimum requirement and that none are mutually exclusive, the writer considers that capability # 5 *Emotions* would most likely evolve in tandem with and be more fully realised

when consideration of life pathways and opportunities in capabilities #6 are underway. As emotional maturity is realised so life opportunities can be defined and then realised too.

All prisoners, including those with hearing loss, have proven they are unable to either form or consistently apply the conception of the good by the fact that they have breached society's rules to the extent that they are now incarcerated. This does not take into account prisoners who are convicted in error, which is a reality for some who have hearing loss and are mistakenly considered to be acting inappropriately and convicted for crimes such as breaching the peace.

But if they have hearing loss that is not recognised during their childhood how can they develop their abilities to understand their environment and to apply sound practical reasoning from doing so? This clearly underscores the need for regular, mandated, hearing screening for all children at regular intervals throughout their childhood, a notion that will be discussed further in chapter five. Accordingly many prisoners with hearing loss will struggle with the implementation of capability # six, and they will need active support to develop these skills later in life if they have not been achieved earlier.

Nussbaum identified that capability #7, "*Affiliation*", occurs in two parts with Part A "*Being able to live with and toward others, to recognise and show concern for other human beings, to engage in various forms of social interaction; to be able to imagine the situation of another. (Protecting this capability means protecting institutions that constitute and nourish such forms of affiliation, and also protecting the freedom of assembly and political speech* [and Part B]…*Having the social bases of self-respect and nonhumiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin*" (Nussbaum, 2006, p. 77).

In consideration of Capability #7, Part A, a sector environmental scan as done in full further on in this chapter shows that people with later-onset hearing loss rarely join the Deaf community and do not learn to communicate through sign language as they are dominant and preferential verbal communicators. Some have endeavoured, unsuccessfully, to learn sign language in an effort to overcome the marginalisation and isolation. But this has proven difficult because brain plasticity lessens with age and new languages, whether being acquired through visual or auditory brain pathways can prove difficult to acquire when older.

From observations of this situation both ethnographically as an individual with hearing loss and professionally as CEO of the Foundation, it is very evident that those who are hearing able need to actively make space and give support to people with late on-set hearing loss, enabling us to fully participate in society, otherwise we will remain marginalised. Without this individual response from those who have hearing, our ability to effectively socially integrate by using verbal language to contribute will be markedly reduced.

But, if the hard of hearing who are preferential verbal communicators stand up for their right to be included and consulted they run the risk of being denigrated and alienated by those whom they most need support from to participate and achieve social interaction (Nussbaum, 2006, p. 188). [redacted] This paragraph has been removed due to confidentiality.

There are many barriers to the successful implementation of capability #7A in prisoners with hearing loss and it is important to consider how prison authorities can protect the prisoner's right to the freedom of assembly and political speeches. It would appear that to deny prisoners the right to these particular freedoms is most likely one of the intentional aspects of the punishment meted out by society for the crime the prisoners have been convicted of committing. Accordingly, capability 7 A is most likely unable to be realised by any prisoners.

Capability 7B of the Human Capabilities Approach as defined by Nussbaum is: "*Having the social bases of self-respect and non-humiliation; being able to be treated as a dignified being whose worth is equal to that of others. This entails provisions of non-discrimination on the basis of race, sex, sexual orientation, ethnicity, caste, religion, national origin*." (Nussbaum, 2006, p. 77).

The writer proposes that the provision of non-discrimination on the basis of disability also needs to be added to the list Nussbaum described in capabilities #7B.

In regards to capabilities #7B many people with hearing loss, including prisoners, struggle with having the personal social values of self-respect and non-humiliation as being slow to

understand one's environment and the errors in communication often cause embarrassment and humiliation and a slow but insidious lack of confidence can occur.

Unless they are supported to achieve effective communication it is surmised that prisoners with hearing loss are most certainly not treated as being able to be equal to prisoners who do not have hearing loss. Accordingly, prison management are most likely operating in contravention of the New Zealand Bill of Rights by creating a situation of unjustifiable discrimination (Stanley, 2011). Of note, if capability #7B was realised then, in an ideal world, the social contract could apply as all parties would be treated as being of equal status, able to start at the same place and able to contribute the same as all others.

Capability #8, which pertains to "*Other Species. Being able to live with concern for and in relation to animals, plants, and the world of nature.*" (Nussbaum, 2006, p. 77). Prisoners with hearing loss are often unable to have their basic need for continuing safety met and their need for procreation is very rarely met.

Some prison authorities do run programmes where prisoners are required to raise and train service dogs and there is some confluence between the intent of capability #8 which is 'being able to live with concern for and in relation to animals, plants, and the world of nature" (Nussbaum, 2006, p. 77) as the intent of the prison dog project is to address the lack of empathy some prisoners have for vulnerable parties.

The above project is a significant step in the right direction however this writer contends that prisoners will rarely be able to implement capability #8 as there are few opportunities available to do so.

On consideration of capability #9, "*Play. Being able to laugh, to play, to enjoy recreational activities"* (Nussbaum, 2006, p. 77). Neurologist Oliver Sacks wrote that a *"…creative dialogue, a rich communicative interchange in childhood awakens the imagination and mind,* [which] *leads to a self sufficiency, a boldness, a playfulness, a humor that will be with the person for the rest of his life*" (Sacks, 1990, p. 67).

It is with some poignant regret that the writer acknowledges this is the capability loss most grieved when she developed hearing loss as the ability to judge the timing especially with jokes and laughter and to gain the understanding of communications keenly underscores participation in recreational activities including family relationships. This also highlights why spending time with other people who are hard of hearing is empowering as this need,

though physically experienced, is innately known as is the need for comradeship with others experiencing the same type of communication challenges.

This may well be a very challenging capability for prisoners with hearing loss to achieve and attain and underneath it lies loneliness, marginalisation and in some cases, eventually, depression. Once again, hearing abled society needs to make the space and time available for people with hearing loss to participate.

The final capability, #10, defined by Nussbaum in the Human Capabilities Approach as that of "*Control over One's Environment*" (Nussbaum, 2006, p. 77) is defined in two parts, with the first part being political and the second being material.

Capability #10A "*Political. Being able to participate effectively in political choices that govern one's life; having the right of political participation, protection of free speech and association*" (Nussbaum, 2006, p. 77) has extremely limited application in the New Zealand prison population.

In regards to freedom of speech "language and thought, for us, are always personal – our utterances express ourselves as does our inner speech" (Sacks, 1990, p. 74) and to deny us our voice denies us our unique identities as individuals.

As disclosed previously, and will be discussed in-depth later in this chapter, prisoners who have been convicted and imprisoned since 2010 are denied the right to vote in New Zealand's general elections and at sentencing they lose the State's protection for free speech and association. When released from prison, this capability can then be fully realised again. Accordingly, prisoners do not have control over their own environment and capability #10 cannot be applied for the duration of their incarceration.

The second part of capability #10 is "*Material. Being able to hold property (both land and movable goods), and having property rights on an equal basis with others; having the right to seek employment on an equal basis with others; having the freedom from unwarranted search and seizure. In work, being able to work as a human being, exercising practical reason and entering into meaningful relationships of mutual recognition with other workers*" (Nussbaum, 2006, p. 77).

Realistically, whilst imprisoned, all prisoners will have this capability diminished or extinguished. The key question though is, to what extent will a prisoner who has hearing loss be prepared by Corrections to be able to implement this capability upon release?

Prisoners with hearing loss are recognised as being at a lower status to other prisoners and unless they are actively supported by Corrections Probation Service to achieve rehabilitation for their hearing loss, employment will be difficult to attain and many of the other human goals as outlined may well remain as aspirations rather than be realised.

Having reviewed how the 10 capabilities apply individually to prisoners with hearing loss consideration is now given to its application as a single unit. When looking at them globally, it is evident that the ability to communicate underscores and is key to all of the capabilities being effectively implemented both singly and multiply.

Nussbaum also considers that the capabilities list needs to be open-ended with the possibility of re-thinking and revising it through deletion or supplementation of capabilities as needs arise and they need to be broad and generalized so they can apply in all situations, which is the same concept underscoring the development of the doctrine of human rights (United Nations, 2015b).

The Human Capabilities Approach which is "…the opportunity to achieve valuable combinations of human functionings - what a person is able to do or be" (Sen, 2005, p. 153) has been applied to prisoners who are hard of hearing and it is evident that their needs and rights are not adequately addressed in terms of citizenship and disability. Through the application of the Human Capabilities Approach the specific freedoms required to ensure presenting circumstances support prisoners to thrive can be seen.

Of note though, Nussbaum diverges from Amartya Sen (2005, p. 152) in that she is concerned with rights rather than human functioning. To address this gap Sen (2005, p. 152) suggests it is best to view **human rights, as rights to specific freedoms** and **human capabilities as specific freedoms that others must safeguard and expand**. He supports the notion that process and opportunity are two specific elements of all human rights that require separate recognition and that it is the opportunity element that aligns well with the Human Capabilities Approach as outlined by Nussbaum (2006, pp. 76-78).

On considering both perspectives, it would appear that surely one is essential for the other to exist, as opportunity must present for the practical functioning to then be applied. Furthermore, both must apply equally to all from birth so that individuals have the same ability to manage the benefits and risks of both favourable and unfavourable circumstances. Nussbaum contends and the writer agrees that the central Human

Capabilities Approach is universal and as it upholds human dignity it can also be classified as a human rights approach.

In closing this section on human capabilities, Sen (2005, p. 154) endorses the notion that this approach offers the individual the opportunity to use the capabilities and to do so individually or in combination. This is of particular importance when considering the needs of prisoners who often present with complex needs. These needs can be addressed by recognising their combined capabilities and developing specific cross-capabilities programmes to ensure their capabilities are addressed as much as possible in preparation for re-entering society or contributing within the prison environment in the case of long termers.

Public source media information and relevant Acts that relate to enhancing life opportunities for prisoners with hearing loss will now be considered. Then, it will be followed by environmental scans of the cultural-linguistic Deaf sector that promotes the use of New Zealand Sign Language and the Hard of Hearing sector that supports the use of technology including cochlear implants and hearing aids.

In addition to the previously outlined review of how the Human Capabilities Approach applies to prisoners with hearing loss, an examination of discrimination and stigmatization in the context of identifying whether the State has a duty to provide for the powerless within the social contract will also occur.

2.2.2 The Human Capabilities of Children with Hearing Loss

The opportunity to apply a wide range of human capabilities as defined by Nussbaum, (2006, pp. 76-78) can be severely inhibited when a child has hearing loss that is un-diagnosed; managed inappropriately or unmanaged.

They will be denied a wide range of capabilities including the opportunity to communicate by using technology and or sign language; to understand the ebb and flow of human relationships and to be safe from domestic violence as children with disabilities are known to be at greater risk of this. Most importantly, children need to be able to effectively use their senses to imagine, think, and reason and as well access education, religious choices, literature, music etc., as all will need to be delivered in a format and supportive environment so that they can understand and learn. In fact, it does raise the question of whether the capability of a life worth living is able to be applied in these circumstances.

Also, currently in New Zealand, children who have Auditory Processing Disorder, are being denied the opportunity to develop capabilities to use their minds to protect their guarantees of freedom of expression because they will find it challenging to effectively socially interact with others and understand the emotional responses of other people.

As a consequence to their lack of voice and inability to effectively and appropriately engage with society, they are being marginalised by their peers. They experience a loss of self-respect, humiliation and discrimination, because of disability, culminating in a loss of social status. Sadly, they also experience a loss of the capability to play effectively with peers as they cannot participate on an equal basis without pro-active and appropriate support to do so. Life is most likely bewildering and lonely and this set of circumstances surely sets a child up for failure, unless they are provided with appropriate rehabilitation.

Thus pediatric hearing loss, including Auditory Processing Disorder, needs to be considered to be more than a disability or a medical diagnosis because "[p]rofound childhood deafness is …a cultural phenomenon in which social, emotional, linguistic, and intellectual patterns and problems are inextricably bound together. When communication goes awry, it will affect intellectual growth, social intercourse, language development, and emotional attitudes, all at once, simultaneously and inseparably" (Sacks, 1990, p. 51).

[redacted] This paragraph has been removed due to confidentiality.

But it is known that "…shame is the pain and pride is the pleasure through which we are socialized and learn, from early childhood onwards, to behave in a manner that is socially acceptable" (Wilkinson & Pickett, 2010, p. 41). Accordingly, a child who cannot hear to the degree required to acquire socialization will, undoubtedly, be marginalized as they fail to learn what is required to achieve social integration and status.

They need to "feel valued and capable human beings…and crave positive feedback and often react to outright or implied criticism with anger" (Wilkinson & Pickett, 2010, p. 43). It

is evident that in these circumstances the social contract cannot apply, as the child cannot achieve an equal starting point. They will be of a lower social status and a child who feels undervalued and incapable of achieving success is at risk of establishing negative coping strategies, such as angry outbursts, when responding to life capability challenges.

To reiterate, there have been no quantitative or qualitative longitudinal studies analysed to unequivocally prove, as claimed on an ABC Television programme that “hearing loss including middle ear infections in Australian Indigenous children increases their likelihood of ending up in prison” (ABC Television, 2010).

It is recognised that an infant or child who has a full hearing loss cannot function as expected or indeed required unless compensatory communication support methods such as cochlear implants, hearing aids with or without remote microphone capacity and/or access to sign language and captioning are provided. The writer ventures the notion that a child with partial hearing loss will also struggle to function as expected unless they too are supported to achieve their capabilities.

Prior to the introduction of the New Zealand non-mandatory Newborn Hearing Screening Programme (NHSP) (National Screening Unit, 2014) which was rolled out in full in 2011/2012 it was not uncommon for children with severe to profound hearing loss to remain unidentified for up to 4 years. Thus, it was most unlikely that the social contract could be applied to this group of children as they were unable to achieve equal status and reciprocate with other parties to the social contract. But, the introduction of the NSHP dramatically altered the life outcomes for many babies who achieved early diagnosis and have since been able to realise their capabilities.

But within a couple of years of the NHSP being introduced there were significant issues identified in regards to under-resourcing of the programme and insufficient training of hearing screening staff which led to false negative test results. The NHSP was reviewed then redesigned and the issues as identified have been addressed.

The delayed detection of congenital or genetic severe to profound hearing loss in the New Zealand neonate population has now been resolved which partially realises Bowers recommendation that “efforts to recognise and treat ear disease in children deserve the fullest support of the community” (Bowers, 1981, p. 17).

Unfortunately, the NHSP has only partially addressed the issue of identifying hearing loss in neonates because hearing screening is not mandatory therefore some families withhold

consent to screen and some marginalised families are not being reached by the programme. Furthermore, the NHSP hearing screening parameters are set to identify if a baby has moderate to profound hearing loss **only**, excluding detection of hearing loss in babies who are born with **mild to moderate** hearing loss.

It is important to note that babies whose hearing screening results meet the criteria for having State funded cochlear implants (CI's), will have their needs for CI upgrades and component replacements met, life-long, by the State, whereas the situation for children with mild to moderate hearing loss, if they are identified at all, is much less certain.

Hearing aids are fully funded for most children except those diagnosed with Auditory Processing Disorder but rarely fully funded for adults in New Zealand unless they meet stringent Ministry of Health (www.health.govt.nz); Accident Compensation Corporation (www.acc.co.nz) or Veterans' Affairs (http://www.veteransaffairs.mil.nz) policies and criteria for funding.

To recap, the NHSP does not identify the milder to moderate hearing losses that can present neonatally and there is no mandatory paediatric hearing screening in New Zealand. Accordingly, there is little certainty of capture by scheduled diagnostic hearing screening and an adult will need to actively seek hearing screening for a child through the public health system. **This situation is entirely unsatisfactory**.

Once again, those born with significant disability, namely partial hearing loss, are not equal parties to the social contract, because they are physically incapable of bringing equal benefits for all in society **unless** they are supported to achieve their capabilities.

Because mild to moderate hearing loss is not detected by NHSP it frequently goes undetected in neonates, which does raise concern at how little is being done in New Zealand to identify, understand and ameliorate the impact of having partial hearing loss.

Although no longitudinal study research has shown unequivocally that hearing loss is linked with criminality, hearing loss is associated with poor social and educational outcomes (Bowers, 1981, p. 17; The Australian Senate, 2010). By the State failing to both identify hearing loss in the milder to moderate range or provide life-long rehabilitation they are minimizing the impact of all types of hearing loss, [redacted]

[redacted] This paragraph has been removed due to confidentiality.

Little is being done proactively in New Zealand to actively identify hearing loss at any age group past the neonate stage and ensure improved life outcomes. This is explored further in chapter four.

To conclude, whether the family elects to apply New Zealand sign language, hearing aids or cochlear implant communication pathways, or a combination of all or some of the modalities, the key issue is in fact to recognise the child has hearing loss. Otherwise, the childs' human capabilities and life opportunities will be narrowed as they become marginalised and struggle to learn, socially integrate and undoubtedly they will likely achieve a lower social status.

2.3 Marginalisation of Prisoners with Hearing Loss

As noted in chapter one, health research indicates the most important markers of psycho-social stress in modern society are low social status, lack of friends, and stress in early life (Wilkinson & Pickett, 2010, p. 77).

These markers are often seen in the social backgrounds of New Zealand prisoners who as adults tend to be "predominantly poor, badly educated, in poor physical and mental health, and from situations of unemployment and underemployment (Scott, 2008; Smith & Robinson, 2006; Stanley, 2011, p. 9).

The 2005 New Zealand Government Prisoner Health Survey (Ministry of Health, 2006) explored the broad status of prisoner health through prisoners self-reporting on their own health and disability status.

Specifically prisoners **self-reported** in the New Zealand Prisoner Health Survey they had difficulty hearing in a group at a rate of 31% or just under 1:3 (Ministry of Health, 2005, p. 120). In comparison, it is reported that between 1970 to 1983 prisoners in United States prisons had between 36% to 48% of hearing loss as identified **by hearing screening tests** (Dahl, 2002, p. 1).

In New Zealand over half of the prisoner population ethnicities are Maori and Pacific people. It is reported that the prison population reflects the most disadvantaged members of society with inmates often being ill-educated; some having mental ill health issues and

as well, asylum seekers who may have a myriad of physical and psychological challenges to contend with (Stanley, 2011, p. 9).

Whilst Dahl (1992) made a valiant effort in British Colombia to raise the issue of prisoners with hearing loss and there have been various efforts made in Australasia since 2009, predominantly the adage of out-of-sight, out-of-mind, appears to be at play with this group of marginalised people in New Zealand. Unless something is done to raise their issues on the national stage it is likely that the current situation of discrimination and stigmatization will prevail.

Many prisoners have childhood histories of neglect and disadvantage and it is reasonable to consider that some hearing losses have occurred either genetically or congenitally and been unrecognised for many years. [redacted]

This paragraph has been removed due to confidentiality.

Other barriers to recognising hearing loss in prisoners include their invisibility from the eyes of public policy makers; they do not have a voice to influence and they are significantly alienated from society because they were shunned in response to contravening society's rules.

However, they are not alone in their marginalisation as they are acknowledged as being a member of the "out-group" (Wilkinson & Pickett, 2010, p. 51) that lives on the fringes of society and are most likely attitudinally isolated as a consequence.

But the attitudinal isolation of this group is also evident from those who have plenty too, as highlighted by de Tocqueville in the nineteenth century who stated that "substantial differences in material living standards between people was a formidable barrier to empathy" (Wilkinson & Pickett, 2010, p. 209). Attitudes such as these are still seen all too frequently e.g. Sean Plunkett Radio Interview of ethnographer (Caption It, 2015).

There is a need to examine the five faces of oppression (Young, 1990, p. 45) to consider if, in fact, the hard of hearing as a group are oppressed in New Zealand. Young defined the five faces of oppression as being exploitation, violence, marginalization, powerlessness and cultural imperialism, and that only one of these criteria has to be present for calling a group oppressed. These five criteria will be individually examined.

Exploitation occurs when the benefits of the work of one group is transferred to the benefit of another group (Young, 1990, p. 48), whereas marginalization, which is thought to be the most dangerous type of oppression happens when expulsion of a whole group of people is allowed to happen. They are denied social life participation and experience severe and unjust material deprivation and Young (1990, p. 55) contends that extermination may also occur.

Next, consideration is given to powerlessness, which is linked to work where people working in non-skilled and non-professional roles are unable to have autonomous working conditions and are not respected. As a result they are unable to be creative in their work, are without authority and are intimidated and find it hard to express themselves (Young, 1990, pp. 56-57). It would not surprise the writer to learn this situation is experienced by many people who are hard of hearing when they are in employment, including prisoners with hearing loss when they are re-integrating into society.

Violence, which can be systemic in oppressed groups who live in fear of unprovoked, random attacks on their property and person, is motiveless and done to humiliate, damage or even destroy the person. Also included “in this category [are] less severe incidents of harassment, intimidation, or ridicule simply for the purpose of degrading, humiliating or stigmatizing members” (Young, 1990, pp. 61-63). It is important to recognise that violence is both a social injustice phenomena, in addition to it being morally wrong and it exists as a social practice which the writer has no doubt occurs in some communities that some prisoners with hearing loss come from and they have experienced it, as victims, on a regular basis. This is because they are at risk of victimization due to their vulnerability and there may be an issue of power, which can thrive as group violence against the most vulnerable.

It is also important to acknowledge, at this juncture, that though family physical violence is an issue for some prisoners with hearing loss, in other families the marginalization is more subtle. Incidents such as birthday and Christmas gifts being of a lesser value than those given to other family members, or not even being given at all to the person with a disability have been reported to the writer. The writer has also heard of tertiary educational opportunities given to siblings who are hearing abled but not to the sibling with hearing loss. Also, the hearing abled siblings benefitted from their parents in their Will but the off-spring who was deaf did not as they were considered less capable of managing their own affairs. Enduring this type of marginalization on a continuing basis is humiliating and

isolating and ensures the person with the disability understands they are of less value to their family and of a lower social status.

The fifth face of oppression is that of cultural imperialism which means to “experience how the dominant meanings of a society render the particular perspective of one’s own group invisible at the same time as they stereotype one’s group and mark it out as the Other”. This description clearly fits with the approach seen in prison services where they have failed to recognise the needs of prisoners with hearing loss, despite being advised of this significant population, yet they have stereotyped them as having behavioural issues thereby marginalizing prisoners with hearing loss (Dahl, 2002, pp. 2-3). Accordingly, in this situation, prisoners with hearing loss are positioned as having behavioural problems and stigmatized by those with whom they do not identify culturally and who do not identify with them.

This situation brings to mind the catch cry of the disability sector worldwide when they worked with the United Nations to develop the Convention on the Rights of Persons with Disabilities (CRPD), of ‘nothing about us, without us’, which would clearly countermand the impact of cultural imperialism as cultural identity and inclusion would then occur.

Two years ago the writer spoke with the New Zealand Minister for Disability Issues advising of considerable bullying being endured by many people with hearing loss and asking if the Government could fund a general public education programme including a video production. The Minister’s comment in response was that she had received the same request from a number of other organizations working with people who have a range of disabilities showing it is endemic in New Zealand, but she did not advise of any action she intended to take.

It is important to recognise the impact of the many facets of the five faces of oppression, which are exploitation, violence, marginalization, powerlessness and cultural imperialism. In addition, Nussbaum (2006, p. 198) reports that Robinson., M. observed that the “[t]rue equality for the disabled…**mandates a change in attitude in the larger social fabric** – of which we are all a part – to ensure that they are no longer viewed as problems, but as holders of rights that deserve to be met with …urgency” (Nussbaum, 2006, p. 198). This is also a stance that has been repeatedly called for by disability sector members (Falk, 2015).

In combination with recognising institutions can and must promote and respect group differences, is the importance of recognising individual capabilities, as endorsed by the legitimacy of human rights conventions and charters. In these circumstances, organisations such as the Foundation (www.nfd.org.nz) need to step up and raise issues through all levels of advocacy, similar to the approach the writer has used when doing auto-ethnography.

When working with institutions such as Corrections it is important to remember that it can "take on a self producing character, and can only be subject to change by individuals and groups who are prepared to phrase their discourse in terms which 'resonate' with the way institutions currently function" (Midgley, 2000, pp. 154-155).

Accordingly, Corrections culture would not be conducive to language used by a national disability body. But if the Foundation fails to speak up on behalf of prisoners with hearing loss and tackle the issues needing advocacy, with the aim of changing of policies at national level for prisoners with hearing loss, to ensure their needs are being heard (The National Foundation for the Deaf, 2015) then the status quo will prevail.

Advocacy done with the aim of bringing about change for groups of people by influencing political and social processes (Prader-Willi Syndrome Association USA, 2015) will be applied in this instance in an effort to have the needs of New Zealand prisoners with hearing loss recognised and addressed. By doing so, the Foundation is applying Kant's formula to act in such a way that it should be universally applicable (Singer, 1993, p. 11).

The Foundation works from the Human Capabilities Approach which queries what an individual is able to be and do and specifies some necessary conditions for a decently just society, in the form of a set of fundamental entitlement for all human beings irrespective of citizenship because the social contract does not offer protection to all. "It does not even claim to be a complete political doctrine" (Nussbaum, 2006, p. 155) "but it does offer a kind of freedom: the substantive freedom to achieve alternative functioning combinations…the freedoms or opportunities created by a combination of personal abilities and the political, social and economic environment" (Nussbaum, 2006, p. 21).

Rawls states (TIJ, 1971 p.123) that he does not assume humans have any rights when in the state of nature but if a person who is free and rational wanted to further their own interests they would accept a starting point of equality (Nussbaum, 2006, pp. 56-57). From that point then, we can all agree, through the social contract, to leave the state of nature

where we were all born equal and work collaboratively for our respective mutual advantages.

But there is a significant problem with this position, as all of the world citizens cannot start equally because their chances and opportunities at birth are assuredly not the same. This has been highlighted by Nussbaum (Nussbaum, 2006, p. 15) who contends that social contract theory fails to address the specific needs of people with disabilities as clearly evidenced by the situation of prisoners with hearing loss in New Zealand, and also by women and animals. These are serious, unsolved, theories of justice that permit the continuance of marginalisation and stigmatization of these groups.

Though Kant contrasts humanity with animality; Rawls believes personhood resides in prudential and moral rationality and contends that ethics require us to go beyond 'I" and 'You'… to the maxim through which you can at the same time will that it should become a universal law… (Singer, 1993 p. 11-12).

Singer reports that "[t]he principle that all humans are equal is now part of the prevailing political and ethical orthodoxy" (1993 p.16). This supports the argument from Nussbaum that all sentients have rights to a life worth living so that they can maximize their capabilities. She argues that animality and rationality are unified in the Human Capabilities Approach (Nussbaum, 2006, p. 155) a notion which this writer agrees with.

The social contract offers rights to some within the democratic state. However those deemed to be unable to contribute or unable to contribute usefully in a functional manner to society are outside the social contract, accordingly, the capabilities of those who are less powerful and without a voice are not addressed within the social contract model. By the application of the Human Capabilities Approach to the needs of people with disabilities including prisoners with hearing loss, women and animals, society will then be able to support them to achieve the same equal status as the previously recognised partners to the social contract and thus the social contract can then apply.

In 2014, the writer was attending a side meeting of the UN Committee on the Convention on the Rights of People with Disabilities (CRPD) in Geneva when it was stated by the Chair of the UN CRPD Committee, Ms Maria Soledad Cisternas Reyes, that the most at risk group globally is now women with disabilities. However, the writer believes that prisoners with hearing loss are another group that need serious consideration globally. This underscores why the work of Nussbaum in the Human Capabilities Approach and the

UN with the application of the CRPD is so vital as both approaches mandate the changing of attitudes and the elevation of the social status of people with disabilities.

Of note though, under the CRPD all people with disabilities have equal rights. The writer had an interesting discussion in this regard with Mr. Paul Gibson the New Zealand Human Rights Commissioner for Disabilities who considered that some people will require more support to achieve the same level of independence depending on the nature of their disability. This is an interesting approach as it upholds the application of the CRPD to achieve equal social status and alleviate marginalisation, ensuring that all can begin at the same starting place, which is in line with the application of the social contract.

2.4 Social Contract Theory

Nussbaum believes the abstract theory of social justice, as defined by John Rawls, should be able to respond to the most urgent problems of the world including giving equal citizenship, political liberties and rights, health care and education to all citizens **without exception**.

Rawls proposed that the core idea of Kant's moral philosophy of reciprocity could also apply in the social contract theory. But, prima facie, this does seem to create tension because reciprocity does conflict with the notion of furthering one's own interests even though Kant tried to address this by ensuring respect was factored in as well.

Though the social contract doctrine certainly offers basic political principles that underscore the Western tradition of liberal political philosophy and have broad and deep impact on our political systems, it cannot address the issues of inequity faced by women, people with disabilities such as prisoners with hearing loss and animals. As it is a contract, it gives support only to those who can give support back and it is most definitely not rights based as the powerful will not share their power to support the weaker, marginalized groups to achieve equal contractual status.

If the powerful will not recognise the needs of the weaker or marginalised in society by sharing their place of origin to ensure all can achieve an equal starting place in support of the social contract how then can the needs of the marginalized be realised?

Nussbaum believes that even though Rawls says he does not adhere to the notion that humans have any rights in the state of nature, his writing shows his readers that in fact he

does, therefore one solution to this dilemma is for the State to recognise the minimum rights of each citizen, no matter their starting position.

Another philosophical approach defined for consideration when seeking political recognition for women and people with disabilities, but not animals, is that proposed by philosopher Hugo Grotius (1625) who wrote about the natural law approach in On the Law of War and Peace which he linked to the Roman and Greek stoics (Cicero and Seneca) (Nussbaum, 2006, p. 21).

He believed that humanity was best-described as requiring moral worth, dignity, an overwhelming drive for social connectedness and a peaceful life with people of similar background and intelligence. He described two levels of need, that of moral worth and dignity being an imperative and the other of social connectedness being a developmental drive.

To recognise the need for justice by women and people with disabilities, including prisoners with hearing loss, it appears that a link needs to be formed between Hugh Grotius's natural law theory of moral worth and dignity and an overwhelming drive for social connectedness and that of the social contract theory proposed by John Rawls which is based upon the notion that rational and free people would accept being in a position of equality with all others if it furthered their own interests.

From that stance, Nussbaum views the Human Capabilities Approach as the link between the social contract theory and the human rights approach because the need for political representation and justice for women and people with disabilities can then be addressed (Nussbaum, 2006, p. 78). In line with the CRPD, "[the] capabilities list starts from an intuitive idea, that of human dignity, that is already basic to constitutional framing in many nations of the world" (Nussbaum, 2006, p. 55).

Of note, the central Human Capabilities Approach has been developed to be a partial moral conception, a term defined by John Rawls, which means it is free standing and is not grounded in the metaphysical divides of religion and culture as it transcends both of these.

By defining the capability but not the delivery of it, as that remains the responsibility of the individual citizen, pluralism is protected even though some health advocates have differing views on whether the goal should be capability e.g. the capability or freedom to make healthy or unhealthy life choices, or function. In this situation the State funds the choice on

what healthy options are to be made available, for example the State funded non-mandatory neonatal hearing screening programme and the individual (or their parent or guardian) chooses whether to use this service option or whether to access it from another service provider and pay for it themselves or to not access it at all and the baby is not hearing screened.

Whilst Rawls social contract theory and the Nussbaum Human Capabilities Approach share a common intuitive starting place they differ procedurally and converge again at the point of meeting the needs of women and people with disabilities. Nussbaum defined four areas for further discussion when considering the notion of applicability, with the first being the circumstances of justice; the second about being free, equal and independent; the next being the purpose of social cooperation and the fourth is the motivations of the parties.

When considering the circumstances of justice, social contract proponents state that justice offers rationality in a Well-Ordered Society when people are able to use it to exit the state of nature and develop a social contract to achieve mutual advantage, whereas the capabilities approach stems from Aristotelian/Marxian concepts of the human being as a socially connected, political and social being and asks whether their life is being lived with dignity.

Though prisoners with hearing loss cannot be free and independent, it is vital that they are enabled to begin at the same point when participating in social reintegration and recidivism prevention programmes as their hearing abled prisoner peers. **This point is not negotiable** because if this requirement is not met, prisoners with hearing loss will probably continue with poor social integration and being at-risk of travelling on the recidivist path, possibly due to a lack of capabilities support.

In the social contract model there is an expansive understanding of the word free as it applies to freedom of choice for the way of life and political leanings. In comparison the Human Capabilities Approach differs because it recognises a wider range of freedoms that are enjoyed by both animals and humans.

In regards to power and experience, the social contract theory certainly requires participants to be equal and come from the same starting point of origin but the Human Capabilities Approach does not because with this concept these rights are innate and apply to human diversity as experienced over a changing life span. Then, when considering independence, the Human Capabilities Approach applies in that we are all

bound by the political interests of others and we share common goals. This means that we are dependent on others during specific life phases and some, with disabilities may remain dependent for the whole of life. In comparison the social contract theory is one where the individual gives up their independence to gain a mutual advantage and in doing so they expect citizens to be equal and able to maintain their independence over a lifetime.

2.4.1 Social Contract Theory: Application with People who have Disabilities

In considering the conceptual purpose of social cooperation, the social contract has been developed to achieve mutual advantage for a select able few. Rawls has endeavoured to apply benevolence or justice for all through the Veil of Ignorance, which is a situation where he has defined that all parties to the contract are equal in their lack of knowledge on their social position and power and intellectual capabilities. In contrast Nussbaum believes the capabilities approach intrinsically includes the benevolent sentiments from the beginning and if someone experiences a capability failure, compassion will then occur *"as a part of her own good"* (Nussbaum, 2006, p. 91).

Moving from the global perspective to the needs of the individual, where it is considered that "[h]uman beings are held together by many ties: by ties of love and compassion as well as ties of advantage, by the love of justice as well as the need for justice…[But r]eal people often attend to the needs of others in a way that is narrow or arbitrarily uneven" (Nussbaum, 2002, p. 157) and "[t]he tendency of all modern societies is to denigrate the competence of people with impairments and their contribution to society" depicts an unenviable existence for many people with disabilities (Nussbaum, 2006, p. 188).

But "...in this world we need each other, in order to meet our basic needs…and [in discussion] Sunaura explain[ed] that disability is socially constructed through the disabling affects of the way people respond to you…" (McIntyre-Mills, 2014, p. 14). It is evident that "rather than being regarded as mere property themselves, people with impairments and disabilities need to be regarded as dignified citizens who have the claim to property, employment, and so forth" (Nussbaum, 2006, p. 169). If the citizenship rights of people are not protected as in the case of asylum seekers and prisoners then human rights need to be invoked.

Young (1990, p. 42) defined a social group as a specific group who through their practices, way of life or cultural form supports members to have a special affinity with each other because of the impact this similar experience has on their lives. This can be viewed in the

Deaf sector who call their group a community, which is in line with their identity being constituted relationally (Young, 1990, p. 29).

Whilst the hard of hearing are not as easily seen as they culturally align with the hearing abled sector, there is a tacit underlying empathy evident amongst many who are hard of hearing who understand first hand the challenges this sensory loss can cause. Young believed that for every privileged group there is an oppressed one and in New Zealand the oppressed are the hard of hearing and the privileged are the hearing able.

The National Foundation for the Deaf (the Foundation) actively promotes and upholds the CRPD which is outlined in Article 3 as:

a. Respect for the inherent dignity and, individual autonomy of persons with disabilities including the freedom to make one's own choices.

b. Non-discrimination.

c. Full and effective participation and inclusion in society

d. Respect for difference and acceptance of persons with disabilities as part human diversity and humanity.

e. Equality of opportunity.

f. Accessibility.

g. Equality between men and women.

h. Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities (United Nations, 2015a).

The Foundation actively works with and for people with hearing loss, supporting them to be their own best advocates. However, if this is not possible and the individual needs an advocate to assist, then, resources permitting, advocacy support and guidance will be given.

It has been identified at the Foundation that often the issue is one where a government policy needs to be challenged to ensure it is changed to reflect the best interests of people who are deaf or hard of hearing and systems advocacy using case examples will be applied through political lobbying. But some of these policy issues are wicked as they are ill defined and rely upon elusive sound political judgment for management.

Rittel and Webber (1973, pp. 160-167) outlined ten defining characteristics of a wicked problem, such as solutions are not true-or-false but good-or-bad; there is no immediate and no ultimate test of a solution to a wicked problem and every wicked problem is

essentially unique but can be considered a symptom of another problem. They also believed there are levels of resolution but the issues are never solved.

To tackle a wicked issue, a policy window of opportunity (Kingdon, 1993a) needs to open which occurs as three streams namely the issue; the solution and a politician prepared to make a policy change. When these three streams converge, change inducing action can be initiated.

When the Ministers with the relevant Parliamentary portfolios have a wicked problem to address and the civil servants responsible for offering policy recommendations are unable to provide the required viable solutions, then the Minister recognises a need "for developing participatory democracy and governance.…[which] extends liberal democracy in that it enables people to develop the policy agenda and to hold politicians accountable, not just by voting them in, but by shaping policies" (McIntyre-Mills, 2008, p. 15)**.**

Indeed New Zealand "[c]itizens are regarded as consumers…but they are yet to be regarded as rightful decision-makers, not merely voters" (McIntyre-Mills, 2008, p. 11). It has been observed at the Foundation that only when the policy problem is too wicked and there is a risk that the Minister who is holding the particular portfolio within which the issue resides will be brought into disrepute that the policy window opens and the consumer advocate is offered truly meaningful engagement through advocacy.

This approach is evidenced in New Zealand by the recent formation of the Auditory Processing Disorder Expert Reference Group, to which the writer was appointed. The Government Ministries of Health and Education developed this group to address the wicked policy issue in this area of policy development and service delivery.

Another significant and concerning barrier to integration is that of social stigmatization causing marginalisation. "Erving Goffman's classic study of social stigma shows again and again that a central feature of the operation of stigma, especially toward people with impairments and disabilities, is the denial of individuality; the entire encounter with such a person is articulated in terms of the stigmatized trait, and we come to believe that the person with the stigma is not fully or really human" (Nussbaum, 2006, p. 191). Thus, oppression is justified and its impact upon those being oppressed, such as prisoners with hearing loss, is minimized and society takes no action to address it.

In its' traditional usage, oppression means the exercise of tyranny by a ruling group…"[but] [i]n its new usage, oppression designates the disadvantage and injustice some people

suffer not because a tyrannical power coerces them, but because of the everyday practices of a well-intentioned liberal society" (Young, 1990, p. 41).

At the Foundation we regularly hear of vast and deep injustices being borne by the Hard of Hearing, caused by "often unconscious assumptions and reaction of well-meaning people in ordinary bureaucratic hierarchies and market mechanisms – in short the normal processes of every day life" (Young, 1990, p. 41).

People who are hard of hearing are often unheard as a result of not being able to ask the question at the correct time and because we miss social cues and do not always know when it is appropriate to speak. But "[i]f you want to ask us how we are repressed, listen carefully to what we are not allowed [or are unable] to say…" (Wadsworth, 2010, p. 152). Then, if others ask the question on our behalf, we may not hear what they ask or if we do, we may not hear the response. This is further compounded by the lack of technology support such as captioning or loop systems, which enable access, being unavailable.

It really is a matter of poor access to society's conversations that impacts us most severely and yet so often, it appears that the hearing-abled have no understanding or recognition of this. Comments such as the derisory and offensive "what's the matter, are you deaf" or "do you have domestic deafness" said "in jest" by the hearing abled are often deeply offensive but if we respond accordingly we risk ridicule for being 'over-sensitive'.

A notable example of this is the Auckland Council circulating a meeting invitation to the disability sector, offering us the opportunity to discuss the Auckland City Plan. On the invitation they advised they would not be providing a Loop System, even though this technology is needed by many hard of hearing participants wearing hearing aids, enabling adequate access to the speaker's voices to understand them. Clearly this is an example of marginalisation which is the social process of becoming or being made marginal (especially as a group within the larger society) (Princeton, 2012).

> "Marginalisation is perhaps the most dangerous form of oppression. A whole category of people is expelled from useful participation in social life and thus potentially subjected to severe material deprivation…[which] is certainly unjust, especially in a society where others have plenty" (Young, 1990, p. 53)..

Also, the retrenchment of the prisoners' right to vote raises significant issues "…of distributive justice [and]…also involves the deprivation of cultural, practical, and institutionalized conditions for exercising capacities…" as seen most obviously with

powerless prison populations who are “situated so they must take orders and rarely have the right to give them” (Young, 1990, p. 55)**.**

In regards to the prisoners’ right to democratic participation, it was interesting to read the Mount Eden Correction Facility (MECF) Panui Prison Magazine of 2 May 2014 report that “[t]here’s also the mistaken belief that people in prison have no right to vote…but people with sentences less than 3 years or on remand Do have the vote”. Having read this, the writer contacted the New Zealand Electoral Commission to verify the facts and they advised that **all those convicted** of criminal charges are now unable to vote.

Following on from that, the writer emailed the Director of Serco to query if prisoner’s on remand could vote and he responded with “…anyone who is a New Zealand citizen or a permanent resident of New Zealand and who is in New Zealand on Election Day, is entitled to vote at the General Election except if they are detained in a prison serving a **sentence** of imprisonment imposed **after** December 2010…. This means that people who are held in MEFC who are on remand and not already serving a sentence are entitled to vote within the electorate where they last resided for a month or more…” (Sands, 2014).

When considering actions as taken by the New Zealand Government, it is evident that prisoners convicted and serving their sentence from 2010 onwards are unable to vote in the General Elections. To recap prisoners with hearing loss, who are already operating under the burden of being multiply marginalised also experience further State induced marginalisation by the 2010 legal amendment to the New Zealand Electoral Act (Parliamentary Counsel Office, 1993).

“Locally and internationally democracy is currently increasingly criticized for not representing the interests of citizens” (McIntyre-Mills, 2008, p. 14). Furthermore the elimination of a prisoners democratic right to vote clearly shows that State oppression causing marginalisation and feelings of futility and powerlessness is being bought to bear on this group and, as well, that the government is not representative of or accountable to all citizens.

“Problems of prejudice, stereotyping, discrimination and exclusion exist because some people mistakenly believe that group identification makes a difference to the capacities, temperament, or virtues of group members ...Oppression, on this view, is something that happens to people when they are classified in groups” (Young, 1990, pp. 46-47). It is not

surprising that, under these circumstances, prisoners become cynical and disillusioned and become further marginalised by their attitudes.

Also, access is frequently denied to oppressed groups. This is highlighted by the fact that Bowers advocated for each prisoner with symptoms of hearing-loss to be assessed and given appropriate disability support to the same level as their non-incarcerated hearing-disabled peers with access being facilitated by prison management.

This has not occurred and the inertia fits with the notion that prisoners are viewed from a pervasively negative stance by the general population. Some believe we "…live in a pessimistic period …[and] it is easy to feel that many societies are, despite their material success, increasingly burdened by their social failings" (Wilkinson & Pickett, 2010, p. 15). If we are indeed in a pessimistic period prisoners, and especially those with hearing loss and other increased levels and types of need may be viewed as unworthy and too much of a burden and the prevailing inertia will continue to apply.

How then do prisoners achieve access and equity, which is "[t]he state, quality, or ideal of being just, impartial, and fair" (Dictionary.com, 2015), given that the New Zealand government has been actively retrenching prisoner human rights? Simply put, they cannot and the question that has to be asked then is: what are the capabilities of prisoners with hearing loss, as defined by what they are actually able to do and be, if their hearing loss remains unidentified?

As a society we need to be pursuing hearing loss identification and then striving for disability equality for prisoners, recognising their capabilities as defined in the Nussbaum Human Capabilities Approach. The aim will be to achieve equal rights, opportunities and status as others who are imprisoned but not hard of hearing. This would then be the equal launching pad for all prisoners with hearing loss to be able to start their rehabilitation and reintegration into society. .

"*The* [New Zealand] *Human Rights Act 1993* (Parliamentary Counsel Office, 2015) provides a direction on what are reasonable accommodations that need to be made to the environment to make it accessible. The Act states that discrimination on the grounds of disability is prohibited and the New Zealand Office of Disability Issues states that failure to provide access to someone who has impairment could imply discrimination on the grounds of disability (Office for Disability Issues, 2015a). Some examples of reasonable accommodation to enable access for prisoners with hearing loss are the provision of

hearing aids, of New Zealand Sign Language interpreters, and, as well, captioning on screens in Court hearings and on other broadcast mediums in meetings.

Bowers stated that “hearing loss in early childhood is known to contribute to poor language development, low educational attainment and behaviour problems” and her research findings clearly outlined prisoners had significant rates of hearing loss and unmet needs (Bowers, 1981).

But inherent in the New Zealand Government funding contracts with both the Corrections facilities and Serco private prisons is **the tacit contract with the general population**, whereby those who are judged by their peers to be unready or unsafe to live amongst the general population are housed and rehabilitated. Clearly, hearing loss rehabilitation is not happening with prisoners who are hard of hearing as their disability diagnosis and the development of appropriately tailored rehabilitation support is by no means routinely occurring.

Accordingly, the continued lack of process for identifying prisoners who are hard of hearing at the onset of the prison sentence is significantly in breach of this tacit contract. This is because Corrections contracts with both public and private service providers, to ensure sentenced prisoners are separated from society, presumably keeping society safe. The service providers are also tasked with rehabilitating the prisoners so that, when they return to society, they are no longer a risk. Corrections is failing to hold up their end of this tacit agreement.

In conclusion, prisoners who are hard of hearing are uniquely vulnerable and there is no mutual benefit to either the government, society-at-large or to the prisoners themselves for their hearing loss to remain unidentified with the consequence that rehabilitation will not be provided, as it was not recognised as needed.

2.5 The Systems Approach

At this juncture the theory of the systems approach and the work of Churchman (1979), Jackson (1991), Jackson and Keys (1984), Midgley (1992), Romm (1994, 1995), Flood and Jackson (1991), Flood and Romm (1996), McIntyre (2002), Ulrich (1983, 1991, 1996/2014) and finally Flood (2010) are now considered.

The systems approach supports viewing the world from the perspective of another. By adding in critical systems thinking it allows for the researchers thoughts to be given to

where the boundaries of the area of concern lay. As there is no a priori set in this regard (Churchman, 1979, p. 17) all researchers need to be aware of the requirement to critique their research within these established boundaries (Midgley, 1992, p. 5). In addition, a 'one size fits all' method or approach to handle the problem of unstable and unreliable data has not been defined and instead researchers usually work from unsound assumptions as there is no a priori or beginning point for analysis of data either (Churchman, 1979, p. 18; Midgley, 1992, p. 12). These two important issues will now be unpacked further to define the possible solutions which will be discussed further in chapter five

There are two fundamental underpinning conditions to research, one being work and the other interaction and from this wide and somewhat loose theory that Habermus projected, Jackson and Keys (1984) and Jackson (1987) developed a pluralist metatheory. In their metatheory they classified systems methodologies according to the assumptions they made about social reality. For example, quantitative modeling methods assume that there is agreement on what the research problem is whereas qualitative debating methods work on the assumption that there is disagreement that needs to be discussed.

To assist with the need to apply questionable assumptions, Jackson defined a set of five commitments being critical awareness; social awareness, human emancipation, theoretical complementarity and methodological complementarity which are expanded and discussed further in this chapter. Early Critical Systems thinkers reduced the five commitments, or continual questioning to three with the two forms of complementarism expressed as a single commitment to methodological pluralism and the commitment to social awareness being viewed as a part of the commitment to emancipation.

Churchman (1979, pp. 13, 149) also stressed the need to challenge and expose assumptions by ensuring we seek out the enemies of our assumptions and then enter into a strong process of rational argumentation and only if our issues survive this, should we then apply them. Ulrich also considered that boundary judgments that incorporate values and facts for inclusion or exclusion which will change when the facts and values are changed and there was a need for identifying and discussing how to address this problem in a systematic way (1996/2014, p. 19).

These are important considerations for this research as it has been an evolving research design that necessitated a flexible response as evidenced through the two stages of Fetterman's ethnography being applied, which will be examined further in chapter three.

To conclude, consideration and thought about the emerging evidence of the continued State neglect of prisoners who are hard of hearing has been framed through the lenses of Rawls social contract theory and Nussbaum's Human Capabilities Approach. This clearly shows that prisoners with hearing loss cannot be partners to the social contract and that the Human Capabilities Approach with its application through a strengths-based practical tool is a sensible option to achieve effective positive change with this at-risk population and warrants further consideration.

As well, a study of the relevant United Nations conventions was done to identify if they were mandated in New Zealand law, or not, and how they are upheld and applied to meeting the needs of this at-risk population. The findings of these considerations show that the application of various UN conventions and charters through New Zealand law is weak and in fact, it may be meritorious to quote the conventions and charters directly in the advocacy work for prisoners with hearing loss to add strength to the rights based arguments rather than rely solely on the laws of New Zealand.

Specific Acts as they applied to upholding the rights to health care and rehabilitation for prisoners with hearing loss were also reviewed and there is strong evidence that the State is required to provide the health care required for prisoners to achieve social integration and reduce hearing loss which may be a significant contributor to the issue of prisoner recidivism.

Also, recently a review was done by the New Zealand Law Foundation in regards to the legal application of whether being a victim of domestic violence could be used as a form of defense in court or as a mitigating factor when being sentenced. The outcome was that it could be applied as a mitigating factor at sentencing.

When applying this line of legal reasoning it raises the question of whether there needs to be a defense recognised in law of a person with significant disabilities who is not receiving recognised rehabilitation supports, who then acts illegally in an effort to realise their State neglected human capabilities. Though it may be a struggle to have this notion accepted at Court as a viable defense for a person with significant disabilities, it is one that could garner merit and consideration as a mitigating factor at sentencing. This notion will be discussed further with the lawyers at Auckland Disability Law.

Also, the international environment in regards to prisoners participating in the democratic process by voting in general elections in countries similar to New Zealand was examined

which showed it is a trend in developed countries for prisoners to be denied this right. Examination of the implications of this rights denial showed the potential for further reduction of State support in areas such as the application of the State health and education budgets to the needs of prisoners with hearing loss which is already being evidenced by them being denied, by policy exclusion, to access funding for hearing aids.

An environmental overview of the cultural-linguistic Deaf community and the Hard of Hearing sector indicates that the Deaf community have limited recognition or understanding of the needs and cultural fit for people who are Hard of Hearing which this writer believes needs addressing.

The key findings though, are that most prisoners have multi-complex issues and that prisoners with hearing loss are likely to present with an all-encompassing loss of human capabilities. This can best be addressed by using a strengths based approach to recognise the potentiality of their capabilities. From that, specific programmes can be developed to ensure their capabilities are recognised and then realised.

2.6 Critical Systems Thinking

The model of participatory action research as suggested by Robert Flood (Flood, 2010, pp. 133-143) is a powerful tool for leading social enquiry and identifying the required policy change and in this instance, it has been applied in combination with critical systems thinking, drawing on the models as developed by West Churchman (1979), Ulrich (1983), and Midgley (2000).

First, consideration will be given to the history of systems thinking and then how it applies to the participatory action research of 100 prisoners on remand at Mount Eden Corrections Facility who present for hearing screening.

The concept of systems thinking assumes that the social construction of the world is systemic and as the concept of systems thinking evolved, it became apparent that it offered grounding for action research by advocating that real social systems existed within the world, through which change could be initiated.

In his commentary Flood (2010, pp. 133-143) defined that system change could occur through the reductionism model of research, whose proponents suggest that when a phenomenon is broken down into its parts, they can be analysed in terms of their cause and effect. However there was some tension at the application of reductionism to living organisms as it allegedly fractured the connection between the research/er with human research participants causing the intangible but vital human spirit a denial of recognition in result findings (Flood, 2010, p. 142).

As a researcher with a long history of applying participatory action research this is a criticism that this writer has heard repeatedly, most often raised by qualitative research participants. In response, to overcome this thought provoking and important challenge to reductionism, it has been recognised that an organism cannot be fully comprehended from it's constituent parts as the whole of an organism is greater than the sum of its parts, a concept which is recognised as the emergence theory.

Accordingly, it is necessary to build up a whole picture of an organism, rather than break it down into its parts, in order to gain meaningful understanding and greater knowledge about it. From this stance then, can emerge qualitative and quantitative social systems research using the concepts of interrelatedness and emergence to interpret social systems, a practice which resonates well with the experiences of people who exist in a systemic world.

Taken one step further, the open systems approach then employs relationship and functional criteria rather than reductionism to analyse the flow of information and energy between organisms and the environment they are situated within. Of note, this flow transpires through interrelated pathways known as feedback loops which Flood (2010, pp. 133-143) described as naturally occurring control processes such as temperature, acidity etc. Two types of feedback loops have been identified, one being the negative feedback with balancing loops and the other being positive feedback with amplifying loops. These loops permit an organism to achieve balance as they promote the maintenance of normal conditions.

Importantly, the aim of the organism is to survive and grow by transforming inputs and adapting to change. When this theory is applied to the human perspective, viewing prisoners with hearing loss as an example, it is evident their feedback loops are out of balance as they have a high level of unmet capabilities and needs that require attention. But the loop back system is a stark and impersonal view of prisoners in which there is no defining line between the natural and social arrangements.

In response to these limitations, von Bertalanffy, a proponent of the general system theory wrote “You cannot simply say…[i]f a child comes from a broken home he will become neurotic and delinquent, he may just as well become a genius, some other conditions, genetic and environmental, being given. But this is precisely the problem of “systems”, the problem of interaction of many and partly unknown variables” (von Bertalanffy, 1969).

von Bertalanffy defined the general systems theory as interaction between many variables and a free dynamic order which was recognised as having two components. The first component was the organismic trend where things are organized with traits as observed for example in psychology and biology and the second component was the mechanistic trend with technological, industrial and social elements using for example control techniques with presenting characteristics such as cybernetics and systems engineering (von Bertalanffy, 1969, p. 37). At the same time the general theory of cybernetics was then theorized by Bateson (1967, p. 29) with “pathways of change” being governed by restraints and equality of opportunity.

Bateson also hypothesized there was no defining line between social and natural arrangements (Flood, 2010, p. 134) which was very similar to the von Bertalanffy theory of open systems “which employs functional and relational criteria to study the whole rather than principles of reductionism to study simple elements” (Reason & Bradbury, 2001, p.

134) and when these two lines of enquiry converged they became known as applied systems thinking.

Then, working from the assumption that systems exist, Checkland (1985) published on the topic of organized use of rational thought which then enabled applied systems thinking to be understood and gave the ability for it to be compared to other models. He contended that research had three distinct elements, namely, linked ideas in a framework; a method to apply the ideas and an area of application and reflection on what had been learned.

When considering the application of these three distinct elements to the research about prisoners with hearing loss, the linked ideas in a framework are that New Zealand has a significant prison population who have hearing loss; that prisoners with hearing loss are marginalised and oppressed, arising from a multiplicity of causes that require exploration and definition; that the Bowers report published in 1981 researched this issue through the audiological perspective that was predominantly quantitative research with a minor qualitative interrogative narrative and made recommendations on how to address it; that the question on whether Bowers 1981 policy recommendations had been applied remained unanswered; there was a need to test another group of prisoners to identify if the rate of hearing loss identified by Bowers persisted and if the Nussbaum list of human capabilities and the United Nations Convention on the Rights of Persons with Disabilities defined human rights could apply to prisoners with hearing loss in 2014.

The method used to investigate and research these linked ideas in a framework are ethnographic participatory action research with elements of quantitative and qualitative enquiry with the area of application being the public policy response and the outcomes being defined in chapter four and recommendations with areas for further reflection outlined in chapter five.

As can be seen in the outline of the questions being asked in this thesis, applied systems thinking considers the structure of stable, functional units and when a problem arises it is necessary to carry out an intervention by entering the system; identifying the problem and the solution to be sought followed by the desired outcome.

The next area for consideration is systems dynamics which focuses on developing models of real world systems and improving problematic behaviours with the solutions being defined mathematically and diagrammatically. This was taken one step further by Senge in 1994 when he applied systems dynamics to organisational learning. He identified that for

an organisation to be a learning one that creates its own future through expanding its capacity it needs to apply or adopt system thinking.

Systemic thinking provides substance to the four organisational capabilities , firstly through personal mastery with world connectedness and interdependencies between our actions and our realities; secondly through mental models which test assumptions to see if they are systemically flawed; thirdly by clarifying how shared vision radiates through collaborative feedback processes and fades in conflictual processes and finally team learning where discussion and dialogue identify positive synergies where the whole becomes **greater** than the sum of its parts or negative synergies where the whole becomes **less** than the sum of its parts.

Though these four organisational capabilities are internally focused on an organisation, if it was a truly functional and effective organisation it would show the impact of these elements externally by being a positively networking, outputs focused, robust, dynamic and flexible organisation that was engaging in discourse both internally and externally.

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Next for consideration is the combination of systems thinking with action research which offers the socio-ecological perspective and is often referred to as the open systems thinking model as identified by Tavistock et al in 1951. Whereas von Bertalanffy viewed environments as random, in the socio-ecological perspective they are viewed in terms of lawful relationships in an environment with a causal texture which Flood identifies as being of a turbulent nature at this point in time (Flood, 2010, p. 136).

Turbulent causal textures arise as a consequence to the unintended impact and ripple effect of managers' actions and decisions resulting in a situation becoming volatile and linked in unintended ways. This then changes the environment; in the socio-ecological perspective allowing lawful relationships to be developed to apply to issues such as poverty, pollution or, in this instance, possibly even the issue of prisoners with hearing loss. From these relationships collaborative pooling of resources from organisations that come from different perspectives can occur. By doing so it may enable the turbulent causal textures to settle. In this research the pooling of resources was effectively achieved by Serco, Life Unlimited Hearing Services and The National Foundation for the Deaf who worked collaboratively to achieve the research outcomes.

There are a number of methodologies that can be applied to the socio-ecological systems perspective that offer frameworks to new ideas and the initial step is to begin establishing boundaries of the environment within which the system resides, remembering though that as more information is discovered boundaries, which focus on the interrelatedness of actors, can then move. Lawful relationships are then defined between the "actors in the system, between the system and the environment, and in the environment. Value propositions are formulated" (Flood, 2010, p. 136).

In the process of formulating the values proposition, dialogue to discover matters and issues that need addressing which are then sorted through will enable the development of appropriate strategies and action. Considering the world through representational tools enables sense to develop from uncertainty and chaos. But, in these tools very little is said about the less visible processes that occur in areas, for example, power struggles, political trading and cultural affairs and disability access to name but a few. Accordingly, the belief that there is a concrete social world is now being regularly rejected in favour of the notion that there are a wide range of systemic qualities, such as those identified in the Human Capabilities Approach and human rights, upholding people's existence.

In this regard, Checkland argues that it is better to view systems involving humans in the same context as those involving emergent systems but West Churchman refutes this, alleging that to do as Checkland promotes will incur significant moral dilemmas. Interestingly, Flood, in response, then sensibly recommends that practitioners of action research learn and understand emergent systems and, as well, the moral dilemmas that can arise when they are being applied in systems with human involvement (Flood, 2010, p. 137).

Consideration of the soft systems thinking, which significantly diverges from the structural systems approach is followed by examination of how this approach can apply to systems research involving human subjects but first the definitions of systems thinking and systemic thinking will be clarified.

Systems thinking is an objective notion that contends systems can be identified and thus improved whereas systemic thinking is a subjective notion, of which soft-systems thinking is one type (Flood, 2010, p. 139). In 1990 Checkland and Scholes identified two subtypes of soft-systems management, with one being to guide participatory action research and the other to be applied day to day in the usual work of an organisation, helping to make sense of the chaos through logical and culturally based analyses.

The soft-systems approach is recognised as an interpretive theory which defines reality as people's construction and interpretation of their lived experiences through their intentions and perceptions. This approach analyzes situations through an intellectual framework that considers action concepts and then arrives at a real explanation of what is in the minds of the people involved from which, meaningful action can then be taken.

It is important to note though that the above reported action concepts are only visible within the deep context of social rules that lead to social practice which are supported by the constitutive meaning that offers understanding and construction to people's actions (Flood, 2010, p. 138).

From this, Flood contends that to get to grips with soft-systems thinking involves building clarity from constitutive meaning, social practices and actions. He reports that models are not to be taken as representative of reality as they act as a pair of spectacles from which we can peer through and interpret reality by studying the cultural aspects of the context as well as the human perceptions and interpretations within it.

Proponents of soft-systems thinking believe that to achieve a real comprehension of any action, it necessitates the involvement of all stakeholders, which in this instance includes the researcher; prisoners with hearing loss and any other parties the research findings will impact on, for example the hearing screening therapists. This is also an essential component of action research and herein lies the deep underlying basis for the relationship between systems thinking and action research, because soft systems thinking provides a wide range of tools and methodologies to participatory action research.

The subtype of soft-systems methodology as applied to participatory action research is usually described in a seven-stage process with the first stage being recognition of a problem that causes unease in a number of people, who then want to explore it further with the notion of improving the situation.

With regards to this research, the recognition of a problem that caused unease was when the writer chanced upon the Bowers Report and discussed the prisoner status quo with Professor Peter Thorne, Foundation Council Chairperson.

In stage two the problem is expressed, though it is essential that the issue is not rigidly framed as this could cause a loss of original thinking and the development of novel issue resolution designs would be impeded. This stage was applied to the research in discussions with Associate Professor Janet McIntyre at Flinders University and with the research key contacts as identified further on in this chapter. From this grew the notion of combining recognition of the issue of prisoner hearing loss with marginalisation, human capabilities and human rights as stated in the Convention on the Rights of People with Disabilities.

In stage three real world systemic thinking proceeds, framed by identifying possible human actions within systems that can lead to issue resolution. “Stage 3 develops root definitions of relevant systems. Root definitions are built around the worldview that states the constitutive meaning underpinning the purpose of a human activity system… . Customers, actors and owners are subsequently named [and] [e]nvironmental constraints are then taken into account” (Flood, 2010, p. 138).

This was the longest stage of the research, with many iterations of the research ethics applications being submitted to Corrections and then repeatedly rewritten as required, in an effort to progress the research. However, this stage culminated in the environmental constraint of Corrections declining the opportunity to participate being realised and the

Prisoner Action and Rehabilitation Society withdrawing as a consequence of Corrections actions. Discussions with a wide range of people followed, with the aim of finding another path forward and eventually Serco overcame this significant constraint by agreeing to participate.

During stage 4, conceptual models are drawn, using the root definitions as identified in stage 3. The conceptual models are basically the verb or action describers of human action systems, which are listed systemically enabling the drawing out of the feedback loops that define the human activity system interactions. When applied to the prisoners with hearing loss research, at this stage Serco and the writer met three times, and on two occasions Serco's Director of Health participated in the meetings too, with the aim of defining the human action systems required to identify the rate of hearing loss in prisoners. It also involved review of the data required and the information needed from prisoners.

In stage 5, the conceptual models drawn in stage 4 are compared to the issues as expressed in stage 2 and wide ranging, general discussion is held to ensure the applicability of the models, the implication of their use and to identify possible changes that may be required. Once again, when this stage was applied to the research, wide discussion was held with Serco, Life Unlimited Hearing Services and the Board of The National Foundation for the Deaf to ensure they were able to support the ethnographer and or participate in the proposed participatory action research of testing 100 prisoners with hearing loss. All stated their belief in the need for the research to proceed and their commitment to participate and ensure it was delivered.

Then, in stage 6, the proposals for change are examined in two ways, namely the desirability of the proposed human activity system and the concern in regards to the feasibility of the proposed change are explored, giving thought to the problem, the political interactions and the attitudes that prevail. At this stage of the research, the feasibility, from the perspectives of safe geographic accessibility, financial and human resource allocation, were identified and commitments were made by Serco, Life Unlimited Hearing Services and the Board of The National Foundation for the Deaf to ensure it could progress uninterrupted.

Though stage 7 may indicate it is the end of the soft system management process, in reality it is open ended as in this stage we explore diverging opinions and accommodations between competing interests and so, the process of soft-systems management starts again at stage 1. This stage is evidenced in the research by

Corrections staff who are acting defensively in an effort to discredit the research findings, though a meeting with the Minister of Corrections who happens to hold the portfolio of the Deputy Minister of Health too enabled a frank discussion to occur.

In due course though the implementation of the research recommendations will require further soft system management as the researcher begins the tasks of advocating for their implementation. Though soft-systems thinking and methodology have offered much in the way of incorporating the aspects of humanity into research practice the concern has been raised that it “confines change in social situations to changing people’s worldviews” (Flood 2010, p. 139) and does not, but possibly should be, addressing the prior structures such as politics and financial system that in fact underscore and lead the development of these views.

Also, the soft-systems approach intellectual framework is that of interpretive thinking, where every idea has to be considered as being of equal merit though wide view explorations and discussions can be difficult to put boundaries around, creating difficulties in moving from discussion to practical implementation. The current solutions defined by Flood are that the existing power structures will prevail to close down discussions and ensure their own goals are defined and implementation then occurs as part of knowledge-power and social transformation. This valid concern engendered intellectual consideration and from that discourse emerged critical systems thinking (CST).

Critical systems thinking is defined as having a set of six principles that guide it with the first one being a commitment to the systems idea and the five others being critical awareness; social awareness, human emancipation, theoretical complementarity and methodological complementarity (Flood, 2010, p. 140).

The critical systems thinking major component of critical awareness, which is two pronged, firstly investigates the weaknesses and strengths of various theoretical frameworks and associated techniques and methods and secondly identifies and questions the assumptions and values inherent in system designs. Then, the major commitment to critical systems thinking identified as social awareness defines acceptable and unacceptable social practices and rules and then, the next major commitment defines human emancipation which ensures the inclusion of people’s potential and well-being in the system design.

Flood (2010, p. 140) reports of three issues identified in the critical systems thinking major commitment of human emancipation which are, firstly, the two elements of people's potential and well-being are frequently overlooked in modern day society as the goals of effectiveness and efficiency drive the re-engineering of people; secondly, some people may feel an element of futility when their workforce is being driven by cultural and intrapsychic forces and, thirdly, there is very little meaning being attributed to their participatory contributions by the mighty who hold the power through knowledge.

To address these three concerns critical systems thinkers need to be sufficiently aware to remain detached and not create their own power knowledge base and as well to be informed and able to apply a wide range of tools as available through critical thinking systems. In line with this theoretical complementarity sits methodological complementarity because Checkland believed that each critical thinking systems framework brings with it methodological principles for action.

2.7 Critical Systems implementation through Total Systems Intervention

To offer a system for the introduction of such methodologies and a holistic approach to the research agenda the Total Systems Intervention (TSI) was introduced. The big questions of when to use which methodology and why, have been partially addressed by the introduction of the TSI which continually asks these questions.

Interestingly TSI also proposes that an ideal type categorization be introduced in an effort to stimulate debate, learning and critical criticism about the methodologies that could be used in response to the presenting possible dilemmas and issues. By doing this, researchers then have a vehicle by which their knowledge and insights can be contributed to the evolving methodology design, thus influencing how the future unfolds as they are learning.

TSI ideal type categorizations are modeled within the four following systems: processes; structures; meaning and knowledge-power. The system of processes is concerned with reliability and efficiency of the control and flow of events and if either of these cause concerns then it is the area of processes that requires attention. If there is an issue with the system of structures, which is concerned with the coordination and control of organisations and their functioning effectiveness, then action might be needed to regulate

the degree of emphasis placed on the procedures and rules and how they influence the organizational function.

The next category is the systems of meaning, which considers the impact of the proposed improvement strategies and what steps need to be taken to address these concerns that can present as either polarized viewpoints or a wide-ranging diverse number of views. The final category is that of systems knowledge-power which may need to be addressed through the recognition of entrenched patterns of behaviour and disempowerment of those who have too much power and empowering of those who need more, thereby effectively introducing a power balance. From these actions the critical systems thinking approach then becomes efficient, effective with meaningful actions and the power is balanced.

Then, to achieve the holistic approach that reflects the inclusion of humanity in the research model the complexity theory introduces the spiritual holistic element. The complexity theory is a form of systemic thinking that explains "the vastness of interrelationships and emergence in which people are immersed is beyond our ability to establish full comprehension" (Flood, 2010, p. 141) thus offering us a notion of logic as to why the inclusion of humanity as part of our systems understanding remains a mystery and eludes our full comprehension. But, does such a lack of comprehension permit the continued application of reductionism to groups such as prisoners with hearing loss, without having to apply critical systems thinking and recognising their life-time needs as a "whole person"?

Prima facie, this appears to be the justification applied by Corrections however, their apathy towards prisoners with hearing loss is not supported by the writer who instigated the application of qualitative research, which is multi-method in focus, cuts across fields and subject matter and is appropriate to this research because it requires working across disciplines and taking into account the lived experiences of the research subjects and involves:

> "…an interpretive, naturalistic approach to its subject matter. This means that qualitative researchers study things in their natural setting, attempting to make sense of, or interpret, phenomena in terms of the meanings people bring to them. Qualitative research involves the studied use and collection of a variety of empirical materials – case study, persona experience, introspective, life story, interview, observational [and] historical … – that describe routine and problematic moments and meanings in individuals' lives. Accordingly, qualitative researchers deploy a wide range of interconnected methods, hoping always to get a better fix on the subject matter at home" (Denzin & Lincoln, 1994).

The writer used a mixed method approach when the Life Unlimited hearing therapists worked with 100 prisoners, so as to be able to assess the extent of the issue of hearing loss in self-selected prisoners.

From this research it is evident that public policy advocacy responses, designed to raise the profile of the needs of an at-risk group require both qualitative and quantitative data. Prisoners with hearing loss required the application of quantitative research methodology to indicate the number of prisoners in need and qualitative data is needed to understand their lived experiences and to enable client-focused strengths based appropriate programme development and delivery.

John Stuart Mill (1843/1906) urged social scientists to copy the harder, quantitative sciences in an effort to generate more valid knowledge that could gain greater acceptance by academia and society (http://plato.stanford.edu/entries/mill/#SciMet). He believed it would also remove the social sciences from the shackles of the philosophical and theological theories that constrained them.

Since Mill's recommendation there have been five historical periods recognised in the evolution of qualitative research with the first being the traditional period from the early 1900's through to World War II when researcher's reports were thought to offer objective, reliable and valid results from studies of others, generally foreigners. These periods will be briefly outlined, to show the range of research models available today and why the writer has chosen the models applied in this thesis.

The next period was the modernist phase covering post World War II through to the 1970's when there were many attempts to formalize the methods used and reports were framed in positivist and post positivist discourse. There was an active movement to maintain firm lines of distinction between quantitative and qualitative research models. However, the modernist phase ended in 1969 when it was realised that qualitative research methodology had expanded widely to include methods, paradigms and strategies all of which blurred the boundaries of what was and what was not qualitative research hence the name for this period is 'Blurred Genres'. This period goes through to 1986.

It was at this time that ethnographic action was recognised as a component of qualitative research as was qualitative interviewing. It was also during this period that Geertz proposed the boundaries between the humanities and social sciences were merging and the essay as an art form was replacing the scientific article (Denzin & Lincoln, 1994, p. 9).

In 1986 a new period emerged, named the Crisis of Representation period or fourth moment, where research and writing were more reflexive and raised questions about the issues of race, gender and class with issues such as narrative objectivity, reliability and validity coming under strong scrutiny. Experiments at this time approached the line between qualitative and quantitative research with social criticism focusing on nation-state politics and technologies of mass communications.

We are now in the period described as ‘A Double Crisis’ (Denzin & Lincoln, 1994, p. 10) where, sadly, ethnographers are required to legitimize and represent their work in the social sciences. The two assumptions, that the ethnographer can directly capture the lived experience and then write it up in their narrative are under direct attack. In fact, in some quarters it is alleged that the ethnographer is also the creator of the narrative text content because of their degree of influence.

It is important to recognise that all of the research methodologies outlined or attributed to the time periods outlined above are still in operation today either as a point of discussion; in practice or as a legacy. Researchers are able to attribute their methodology to any of the research types that sit within these time frames, which offers an embarrassing wealth of choices. It is also important to recognise that qualitative research is not objective or neutral as the gender, race, class and ethnicity influence of the research subject and of the researcher too can shape the inquiry process.

This is particularly significant because quantitative theories have emerged that include context stripping where selected variable subsets have been removed, which, whilst giving greater research control to the scientist, can decrease the range of research findings and diminish its relevance. But, if critical systems’ thinking was applied then consideration to a methodology that would ensure contextual robustness could occur instead.

Others have ensured the exclusion of the purpose and meaning in the research which ensures it is hard scientifically and valid in the purest sense but devoid of the impact of humanity and all of its foibles. In such instances we may see the etic or outsider perspective and views, which may have little or no relativity to the view of the emic or insider.

There is also the hard science practice of increasing knowledge by research abstracts being built on top of the prior theory or abstract. This practice can also be applied by qualitative researchers as evidenced by this research which has been built on top of a

previous abstract as it evolved after the writer read the findings of the hearing loss rates in a group of New Zealand male prisoners in the Bowers report from 1981.

It's reported that "[i]nequities occur when biased or unfair policies, programs, practices, or situations contribute to a lack of equality" (Great Schools Partnership, 2014) and if it were proven that Bowers' research recommendations were not implemented, then qualitative research would be required to identify what needed to be done to ensure the disability induced equity needs of prisoners with hearing loss are addressed.

Qualitative research subtypes vary from "how people make sense of their world and the experiences they have" (Merriam, 2009, p. 13) to observations by participants through narrative case studies and environmental descriptions (Parkinson & Drislane, 2011, p. 3)**.**

This broad definition applies to a wide range of recognised research models e.g. inductive thematic analysis and grounded theory; case study approaches; phenomenology; discourse-conversation analysis, narrative analysis and ethnography which will now be explored in greater depth.

The ethnographic research design is considered to be problem solving through the merging of investigatory elements, that offers a blue print to the researcher by enabling one pre-planned consecutive step to lead on to the next planned step. Also, ethnographic research design considerations usually include essential elements such as timelines, budgets, specific aims, and rationale and history search. It guides the researcher; defines the boundaries and reassures their supervisors and sponsors that the work is well scoped and being delivered according to a defined plan. (Fetterman, 2010, p. 8; Pelto & Pelto, 1970, p. 43).

Pelto's perspective is more of a strategic overview whereas Fetterman's is operational. But, from experience, the writer believes it is vital to ensure both perspectives are incorporated into a research design, enabling multi-level applicability with no gaps thereby avoiding research mission drift (Jones, 2004, p. 96). This is particularly important with auto-ethnographic research as the ethnographer may have significant vested interests that need balancing.

In closing, mention needs to be made of the need for credibility to be given to work such as this, which was verbally referred to recently as "research for the good" (McIntyre, J, 2016) to ensure life-changing policies are developed to enable for example, prisoners who have hearing loss have lives worth living. But, "[t]o serve evidence-based policy making we

probably need to invent a …myth for qualitative work, that is we too have clear-cut guidelines and criteria, maybe not randomized control trials, but we have our criteria" Hammersley, M. (2005a, p.4). This is because "[l]ike an elephant in the living room, the evidence-based model is an intruder whose presence can no longer be denied" (Denzin, K., 2011, p 645).

Though the two models may be delivered side-by-side they are described by Smith and Hodkinson 2005 as being in contradiction (Denzin, K., 2011, p.646).

As a regular examiner of social issues impacting on marginalised sectors, the writer believes the evidence is given through the brave voices of the affected as disclosed in qualitative research narratives and 'ethnodramas' (Denzin, K., 2011, p. 651) as well as through quantitative models.

It is important to acknowledge that no matter the model used, the researchers cultural beliefs, personal bias, gender etc. will influence the research findings and outcomes and recommendations. However, as an autoethnographer the writer's perspective is evident and declared from the outset. Also, in regards to this research, the writer believes that the knowledge of living with hearing loss adds value to the findings as this life experience builds a bridge to the development of appropriate policy responses.

2.8 Sector Review

It is necessary to review the Deaf and Hard of Hearing sectors in New Zealand as the '**D**'eaf and '**d**'eaf/hearing loss communities operate within two highly politicized significantly different sectors nationally, with no shortage of parties making their views publicly known.

Before examining the two largest sectors, Deaf and Hard of Hearing, mention will be made of the communication challenges of Maori who are Deaf and prefer to use Maori Signs to communicate with.

The Office of Disability Issues (http://www.odi.govt.nz/resources/guides-and-toolkits/working-with-nzsl-interpreters/1-maori-deaf.html 30/11/15) reports that "Māori deaf people constitute a large proportion of the deaf community in New Zealand (and at a higher percentage than Māori in the general population). New Zealand Sign Language is used by Māori and Pākehā [D]eaf people alike. Within New Zealand Sign Language, there is an increasing vocabulary of signs for Māori-specific concepts. If services specific to Māori are available, Māori [D]eaf people may prefer to access these services through a

sign language interpreter. Where the spoken language in the situation is English, Māori [D]eaf people can access services through a New Zealand Sign Language/English interpreter.

In situations where Māori is being spoken, an interpreter who is skilled in New Zealand Sign Language, Māori and English is needed. These people are known as trilingual interpreters. Currently, very few New Zealand Sign Language interpreters are qualified to interpret from and into Māori…"and, as well, the person needing the interpretation will need to organize the interpreters' payment.

The writer, in discussion with two New Zealand Sign Language Interpreters on November 27, 2015, both of whom work in the Auckland region, was advised they never get called to work at MECF. The writer also asked the Captioner who transcribes meetings and events for The National Foundation for the Deaf if they were used by Corrections and she advised she had only been called in once and that was when the defendant's Legal Counsel was Hard of Hearing and required her services.

Deaf Aotearoa New Zealand is, a non-government organisation that is a registered charity and represents some of the cultural linguistic sector or 'Deaf' New Zealanders, advise on their website (Deaf Aotearoa New Zealand, 2015):

"There are two approaches to defining deafness. One based on a cultural/linguistic view and one based on a medical view….The word *Deaf* spelt with a capital D is a noun that denotes a culture and a community. The use of sign language as one's first language is the main characteristic of people who identify with this culture and community. With a small d, deaf, is an adjective which refers simply to hearing loss - e.g. deaf children means children with impaired hearing who may not yet have had contact with the Deaf community... The medical view is based on a condition of a lack of hearing in the range of sound common to most people. Words such as profound, severe, moderate hearing loss are used to show how much a person's hearing differs from the general range. Terms such as hard of hearing can be used to describe people who have hearing loss but who do not choose to be part of the Deaf community."

In fact, the definition of the preferred culture for people who are hard of hearing or deaf is that of being able to communicate verbally and to interact with the hearing abled community. Also there is a grief and loss process evident in some who have partially or

fully lost their hearing faculty later in life which may contribute to the rates of depression observed in the older population with later on-set hearing loss.

To achieve integration with the hearing abled many who are hard of hearing positively support and use medical research and technological advances such as hearing aids; loop systems; hearing aids with FM remote microphones and cochlear implants. This technology decreases marginalisation and increases quality of life and without it the hard of hearing are frequently side-lined from participating by many in the hearing abled community.

It is reasonable to recognise that the hard of hearing sector is one of ***hearing enabled through technology***. Furthermore by applying CRPD Article 9 – Accessibility, individuals aim to communicate in the way that is their culturally appropriate norm. The CRPD overarches all such cultural views as it applies universally, without exception on an equal basis to all people, irrespective of whether they vote in general elections or not.

2.9 Act Reviews

Because Prisoners are having their right to democratic participation through voting legally regressed it is important to do an Act review to identify the legal mandate for prisoners to receive health care and rehabilitation to ensure this remains intact. The Acts chosen for review are those that specifically pertain to prisoners' capabilities and human rights.

2.9.1 Accident Compensation Act (ACC Act)

The purpose of the ACC Act is to provide "… a fair and sustainable scheme for managing personal injury that has, as its overriding goals, minimizing both the overall incidence of injury in the community, and the impact of injury on the community (including economic, social, and personal costs)" (Parliamentary Counsel Office, 2001).

But, the ACC Act Disentitlements Section 121 states that prisoners are not entitled under Part 1 – weekly compensation; Part 3 – lump sum compensation for permanent impairment and Part 4- Entitlements arising from fatal injuries. Prisoners are permitted to receive "limited entitlements…[for] rehabilitation and treatment for their injury" (Parliamentary Counsel Office, 2001).

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In 2012, to address the inequities caused by ACC policies, the Foundation lodged a human rights class action against ACC with the New Zealand Human Rights Commission and worked extensively with parties from across the sector including audiologists and consumer representatives to ensure ACC reversed its' policy in this area.

ACC did reverse their policy decisions of 2010 in regards to the provision of funding for hearing loss rehabilitation and increased the funding for injury and industrial caused hearing loss rehabilitation from 12 million dollars to 19 million dollars per annum.

When analysed, the raw data from the 100 prisoners who were hearing screened at MECF in 2014 shows that 54 of 100 prisoners tested or 54% of the group report having industrial noise exposure and of the 54%, 93% or 50 of the 54 prisoners have varying types of hearing loss. Accordingly, the capabilities of these prisoners needs to be raised by the writer with ACC to ensure the prisoners abilities to achieve successful rehabilitation and the opportunity to achieve social integration and decrease marginalisation is grasped.

Prima facie, it would appear that prisoners are able to access hearing injury treatment and rehabilitation in line with their capabilities for life and health. But, as will be outlined further in chapter 5, this notion is under dispute.

2.9.2 Corrections Act 2005 (Parliamentary Counsel Office, 2014a)

The United Nations Standard Minimum Rules for the Treatment of Prisoners (United Nations, 1977) is enacted in New Zealand through the Corrections Act 2005 where it is stated: "Prisoners are entitled to receive medical treatment that is reasonably necessary; the standard of health care must also be reasonably equivalent to that available to the general public (s75)".

As no legal or operational definition has been given to the term "reasonably", this is a loose legal standard that could be applied to ensure the standard of prisoner healthcare

needs to be sufficient to enable the application of Nussbaum's human capabilities of life and bodily health.

But, as previously identified, Corrections has failed to uphold and fully apply Bowers' (1981) recommendations which would have ensured a reasonable level of diagnostic and rehabilitation services for prisoners with hearing loss, enabling them to reach the same starting place as prisoners without hearing loss when receiving training and support for societal reintegration.

Of note, Section 49 of the Corrections Act requires that every prisoner is assessed promptly after reception to identify any immediate physical or mental health, safety, or security needs. This is done through the Prisoner Health Questionnaire (the MOI) process, of prisoner health and well-being assessment at Serco Private Prisons in New Zealand and through the application of a similar tool in the Corrections ' public prisons.

But, on review, neither service has a specific policy in regards to physical hearing loss screening of prisoners and hearing loss screening questions are not included in the prisoner MOI questionnaires. The prisoner health screening tools do not focus on capabilities, and what a prisoner is able to do or be, instead focusing on the negative concept of impairment, and identifying what is known to be wrong or does not work. It is difficult to say whether this lack of recognition in the MOI is comparative to the standard of health care in the general public as there is a lack of common ground between the two groups in this regard.

Both Serco and Corrections need to analyze whether their respective prisoner health questionnaires can be further developed to become an informative, strengths based tool that could guide and offer structure to meeting the rehabilitation and re-integration needs of prisoners rather than just being used to gather information that will ensure the prisoners survive their period of incarceration.

2.9.3 Corrections Regulations 2005 (Parliamentary Counsel Office, 2014b)

Regulations 71-81 contain further details of health care requirements, including dental service and in particular Regulation 72 could be interpreted as applying to the provision of hearing tests and hearing aids. Regulation 72 states:

> "**Duties of chief executive**
>
> The chief executive must ensure that—

(a) health centres are equipped and operated to provide adequately for the health needs of prisoners:

(b) the health needs of prisoners are promptly met, and that, as far as practicable, the physical and mental health of prisoners is maintained to a satisfactory standard:

(c) [Revoked]

(d) access to adequate medical treatment is available to meet the health needs of prisoners at any time.

Compare: SR 2000/81 r 60

Regulation 72(c): revoked, on 1 December 2008, by regulation 6 of the Corrections Amendment Regulations 2008 (SR 2008/371)."

Evidently prisoners who are hard of hearing are able to access hearing health care through Regulation 72 and the Department of Corrections is able to provide it also through Regulation 72.

Funding of hearing aids is the next point for consideration. Hearing rehabilitation equipment can be provided within strict policy criteria by the New Zealand Ministry of Health, Accident Compensation Corporation (ACC) and Veterans Affairs.

Prisoners with hearing loss cannot gain hearing aid funding support from the Ministry of Health Hearing Aid Subsidy Scheme funding scheme which funds up to two hearing aids, as required, at a rate of $511 including GST per hearing aid, once every six years. They are unable to access this funding because a policy requirement states that the recipient must be in employment or voluntary work for a specific number of hours per week. This is most definitely not a Human Capabilities Approach, rather, it is a fund holding model protective of the public purse.

The Ministry of Health also applies the Hearing Aid Funding Scheme, where the Government will fund the full wholesale price of up to two hearing aids as required providing the person with hearing loss holds a Community Service Card, which is provided when an individual has an income as defined below in Table 2.1.

Table 2.1. Eligibility Criteria for receiving NZ Community Service Card

You may be able to get a community services card if you're…	**And your yearly income (before tax) is…**
Single – living with others	$26,042
Single – living alone	$27,637
Married, civil union or de facto couple – no children	$41,327

Family of 2	$48,797
Family of 3	$59,093
Family of 4	$67,282
Family of 5	$75,302
Family of 6	$84,265
For families of more than six, the limit goes up another $7,898 for each extra person.	

(Work and Income NZ, 2015)

There are a number of other policy requirements to be eligible for Government funding of a full wholesale hearing aid through the Hearing Aid Funding Scheme, such as the person having co-morbidities of hearing loss and other disabilities and also having had hearing loss from a young age. But the greatest barrier to prisoners, after their hearing loss is recognised, is being eligible for the funding of wholesale hearing aids through this Ministry of Health scheme is their lack of eligibility for a Community Services Card.

As a prisoner is specifically disallowed from holding a Community Service Card they cannot be provided with Government funded, wholesale priced, hearing aids which prohibit the full application of the Nussbaum defined human capabilities of life and health. This matter will be raised with the Ministers of Health and Corrections as it needs to be addressed urgently through advocacy appeals for public policy change.

To compensate for this Ministry of Health service gap, Bronwyn Donaldson, Health Director at the Department of Corrections advised the writer verbally in 2012 that if prisoners or their families are unable to purchase the hearing aids outright, the Department of Corrections will purchase them and the prisoner will pay the Department back at a low weekly reimbursement rate. This approach does uphold the Human Capabilities Approach by ensuring the prisoner with hearing loss will have audiological support to achieve what they can be or do and if it is being applied it is to be applauded.

However, recent verbal communications in 2014, with Hill, J., past Council Member of The National Foundation for the Deaf and practicing clinical audiologist through the Auckland District Health Board, where the Department of Corrections takes prisoners for hearing screening, indicate that though Donaldson advises Corrections is filling the gap in regards to the funding and provision of hearing aids, in reality this is not occurring.

This is a serious situation because prisoners who have been identified as having a hearing loss and are diagnostically prescribed hearing aids but cannot purchase them will be unable to fully realise their capabilities. The lack of appropriate hearing rehabilitation can

then be a significant risk factor contributing to a prisoner failing to successfully reintegrate in society, and achieving employment.

This indicates there is a need for further autoenthnographic advocacy to determine Corrections policy, and what is actually happening with prisoners who need hearing aids and are unable to fund them in full when prescribed.

2.9.4 Crimes Act 1961 (Parliamentary Counsel Office, 2015)

Part One, Section 5, Para (1) of the Crimes Act 1961 defines that this Act applies to all offences, for which the offender may be proceeded against and tried in New Zealand. It legally defines crimes and various areas of law including insanity; arresting the wrong person; use of force; self-defense and consent to death.

This Act does not apply to a prisoner with hearing loss and their right to access health care, which would enable them to realise their capabilities of life, bodily health, bodily integrity, sense, imagination and thought to the same level as hearing able prisoners. This means it cannot be applied to address marginalisation and lower social status as caused by the disabling effects of hearing loss.

However, it does raise the question of whether there needs to be a defense recognised in law of a person with significant disabilities who is not receiving rehabilitation supports, who acts illegally in an effort to realise their life capabilities. Though this may never be accepted as a viable defense for a person with significant disabilities, it is one that needs consideration and could be raised in Court as it may be a mitigating factor that could be applied during sentencing.

2.9.5 Electoral Act 1993 (Parliamentary Counsel Office, 1993)

The Electoral Act 1993 was amended by The Electoral (Disqualification of Sentenced Prisoners) Amendment Act 2010, which now makes it illegal for any persons convicted of a crime and detained in prison since 2010 to vote in a general election.

The New Zealand Attorney General, the New Zealand Human Rights Commission and the New Zealand Law Society all state this Act is inconsistent with the UN Bill of Rights and the New Zealand Bill of Rights Act (BORA).

In other Commonwealth countries such as Australia prisoners can vote if they have less than a 3-year sentence; in Canada all prisoners can vote and in the United Kingdom only

those on remand are able to vote. The European Court has said the blanket ban of all other prisoners voting is inconsistent with the UN Bill of Rights (Television New Zealand, 2014).

It has been observed that, if New Zealand is at all worried about human rights then inmates must be recognised as being at the greatest risk of all because they are without profile or credibility in the eyes of the public. (Ministerial Committee of Inquiry 1989:26.3, (Stanley, 2011). The most vulnerable citizens in New Zealand are often found in prison populations which includes those who have mental health issues; the unemployed, or those unemployable due to low education, or immigrants who are detained for being non-citizens.

A number of commentators have reported that prisons are perpetrating wider economic, social or cultural violations of rights as they are being used by the State to mop-up the most disadvantaged and vulnerable citizens, (Carlen and Worrall, 2004; Coyle, 2001; Owers, 2006; 2008; Scott 2008; McCulloch and Scraton, 2009) (Stanley, 2011, p. 9). In addition, the State has further increased their rights violations by legally mandating that prisoners sentenced since 2010 have no democratic right to vote and thus no voice to participate democratically and create their own destinies.

Furthermore, some victim rights campaigners and public commentators appear to believe that human rights are a finite resource, proposing that if prisoners have rights then victims do not and then offenders must forfeit their rights to redress this balance. This approach then denies that prisoners can be victims too and are as entitled to the application of and support given by human rights as every other individual in society (Stanley, 2011, p. 10). In fact, human rights apply to all people, equally, worldwide.

This subject, when raised by the writer, frequently generates quite fierce and emotionally driven debate by people who express a multitude of views, most of which support the view that if prisoners' rights are upheld, then victims rights will not be. As detailed above commentators are reporting they believe that prisoners should lose their right to be considered human and should be instead viewed as **civilly dead** (Stanley, 2011, p. 11).

Civilly dead describes a situation where a person who has been convicted of a crime loses most if not all of their civil rights – in effect they become a non-person (Merriam Webster, 2015; Stanley, 2011, p. 11). This then raises the question of whether, if a person is civilly dead, it is legal to apply taxpayers funding to the provision of prison

accommodation and health care? Surely not as taxes are paid to fund services for citizens. It's a slippery slope when a State regresses human rights as New Zealand has done because it is one step closer to declaring prisoners "civilly dead" which raises a conundrum of questions in regards to the use of public funds for the incarceration and rehabilitation of prisoners.

When the New Zealand government retrenched the legal rights of prisoners to democratic participation by removing their right to vote if they were sentenced to a term of imprisonment from 2010 onwards, they breached the Universal Declaration of Human Rights and created further marginalisation of prisoners by lowering their capability for affiliation and status in society. They also eroded the limited capability of a prisoner's control over their own environment and being able to participate effectively in the political choices that governed their lives.

The action taken by the New Zealand Government to regress the right for prisoners to vote is a contravention of Article 21 of the Universal Declaration of Human Rights which states:

> "(1) Everyone has the right to take part in the government of his country, directly or through freely chosen representatives.
>
> (2) Everyone has the right of equal access to public service in his country
>
> (3) The will of the people shall be the basis of the authority of government;
>
> this will shall be expressed in periodic and genuine elections which shall be by universal and equal suffrage and shall be held by secret vote or by equivalent free voting procedures" (United Nations, 2015b)."

The New Zealand Government has also placed prison officers in an insidious position, though many may not realise it, where they are required to follow a law which dictates a duty of denying prisoners their universal human right to democratic participation. It's a situation of "superior orders" contravening the Universal Declaration of Human Rights (International Committee of the Red Cross, 2015).

This is able to occur because in the New Zealand Legislature the Bill of Rights Act (BORA) (Parliamentary Counsel Office, 2013a), which is the national Act that expresses the tenets of the Universal Declaration of Human Rights, does not carry sufficient weight or merit to ensure the State laws are compliant with it. Please see further discussion on this issue under the United Nations section of this chapter.

2.9.6 Health and Disability Commissioner Act 1994 (Health and Disability Commissioner, 2009)

The purpose of the Health and Disability Commissioner Act 1994 (the Act) is to "promote and protect the rights of health consumers and disability services consumers, and, to that end, to facilitate the fair, simple, speedy, and efficient resolution of complaints relating to infringements of those rights" (the Act, Clause 6).

Prima facie, it appears this Act applies unfettered to all prisoners with hearing loss and in personal communication by email (Thomas, 2010) with the New Zealand Deputy Health and Disability Commissioner, Tania Thomas, she advised that "[p]risoners, on a case by case basis, are covered by the Code of Rights in terms of the quality of services they have received - access to health and rehabilitation services is not covered by HDC Act" .

Accordingly, this Act does not apply to a prisoner gaining access to hearing screening, however if they gain access and the service delivered is inadequate for one of the reasons outlined in the Health and Disability Code of Rights then they may have recourse through this Act.

> The Code of Rights as detailed below list the ten rights of health and disability consumers and the duties of health and disability providers. They are:
>
> Right 1: the right to be treated with respect
>
> Right 2: the right to freedom from discrimination, coercion, harassment, and exploitation
>
> Right 3: the right to dignity and independence
>
> Right 4: the right to services of an appropriate standard
>
> Right 5: the right to effective communication
>
> Right 6: the right to be fully informed
>
> Right 7: the right to make an informed choice and give informed consent
>
> Right 8: the right to support
>
> Right 9: rights in respect of teaching or research
>
> Right 10: the right to complain

Though this Act is intended to only cover the delivery aspect of a health care service, the writer attended a session where it was evident Thomas was prepared to ask the hard questions of service providers in regards to waiting lists and inappropriate pediatric services.

Next, consideration is given to prisoners' access to communication support as this is an essential capability underscoring the effectiveness of rehabilitation and societal reintegration.

2.9.7 New Zealand Sign Language 2006 Act Access to New Zealand Sign Language Interpreters

Section 7 of the New Zealand Sign Language Act 2006 defines the right to use New Zealand Sign Language (NZSL) in legal proceedings as follows:

> "any member of the court, tribunal, or body before which the proceedings are being conducted;
>
> any party or witness;
>
> any counsel or other person representing a party in the proceedings;
>
> any other person with leave of the presiding officer" (Parliamentary Counsel Office, 2013b).

Section 4 Interpretation of the New Zealand Sign Language 2006 Act defines **legal proceedings** as meaning:

> "proceedings before any court or tribunal named in the Schedule; and
>
> proceedings before any coroner; and
>
> proceedings before:
>
> a Commission of Inquiry under the Commissions of Inquiry Act 1908; or
>
> a tribunal or other body having, by or pursuant to an enactment, the
>
> powers or any of the powers of a Commission of Inquiry under the Commissions of Inquiry Act 1908."

This Act relates to the opportunity to have affiliation in terms of the Human Capabilities Approach which enables communication thereby allowing a Deaf person to engage in social interactions. It also supports their capability to interact politically and to be given the same right to freedom of assembly as a hearing able person. By using New Zealand Sign Language they will also be able to enjoy recreational activities, share the good times and laugh.

When the Office of Disability Issues reviewed the application of New Zealand Sign Language (NZSL) with Corrections, they were told that the Department facilitates the use of NZSL interpreter services and other communication techniques where effective communication is desirable and necessary in criminal justice settings. Interpreter services

are provided to offenders on a case-by-case basis and in specific circumstances where important decisions affecting the offender are being considered.

Circumstances where interpreter services are most likely to be engaged are as follows: the reception and induction of offenders, the provision of health assessment and treatment, disciplinary matters, psychological assessments and Parole Board hearings.

Key support people may also be needed to interpret more informal interactions with offenders who have hearing loss. The Department contacts the nearest Deaf Association to make necessary arrangements to engage the services of a sign language interpreter and funds the provision of this service, which can also involve travel costs as there may not be an interpreter available in the local area.

It is pleasing to note that the Deaf Association is engaged to ensure a sign language interpreter is provided, however, who provides communication support for a person who is hard of hearing, does not use sign language and requires captioning?

Notification of access to interpreters on Parole Board and Corrections website

On the New Zealand Department of Corrections website it is stated that “[w]hen a prisoner with a disability is received into prison, a plan around how their disability will be managed is developed. This plan takes into consideration their security classification and how they will interact with other prisoners” (Office for Disability Issues, 2011).

The concern with this policy is that prisoners who are Hard of Hearing are frequently unidentified and as such a plan to support their integration, thus reducing their marginalization, cannot be developed in these circumstances.

On the New Zealand Parole Board website it is stated that if an “offender needs to have an interpreter at the hearing they need to advise their Case Officer so one can be arranged for them” (New Zealand Parole Board, 2015).

But individuals who develop hearing loss post-lingually, the hard of hearing population, rarely use NZSL interpreters as sign language is not a form of communication they can easily implement, instead preferring to lip/face read, use verbal skills and read captioning. Accordingly, prima facie through a lack of education, the New Zealand Parole Board does not offer the same level of support to people who are Hard of Hearing as they do to people who are Deaf.

Prisoners who are hard of hearing may need to lip/face read and, given the stress of the situation, a hearing abled support person to re-voice the vocal content from the Parole Board members for face reading purposes. But this is not recognized on the Parole Board website.

The writer discussed this dilemma with Mr. Gee (Gee, 2014), the previous Parole Board Operation's Manager, who advised that when they had prisoners before the Board and it was obvious they could not hear the discussion (but were not clinically diagnosed as having a loss of hearing) they would delay the hearings until adequate communications were established. In circumstances like this, he said they would ensure interpreters were available for people with all disability types and nationalities, as required.

But, as this is not their stated policy is it dependent on an individual response from an employee which is unsatisfactory.

2.10 United Nations Conventions and Charters Review

In 1948 the United Nations developed the Universal Declaration of Human Rights (United Nations, 2015b) which applies to all people, without exception including prisoners. Since then, various other specific conventions and charters have been released that detail the human rights of marginalised groups e.g. women; children and people with disabilities.

Of note, these conventions and charters do not contain any new or different rights as they are all the same as those recorded in the Universal Declaration of Human Rights. These specific conventions and charters have been developed because States were not applying the Universal Declaration of Human Rights to its fullest extent for all of their marginalised populations. This means the human capabilities that can be identified and implemented pursuant to the rights will not be implemented or realised.

These Conventions include the UN Convention to Eliminate All Forms of Discrimination Against Women (CEDAW), (United Nations Human Rights, 2015a); the UN Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006); the UN Convention on the Rights of the Child (CROC) (United Nations Human Rights, 2015c), and the UN International Covenant on Economic, Social and Cultural Rights (ICESCR) .

All of the above UN treaties have to be incorporated into national law through national Acts passed by Parliament and in New Zealand this has been achieved through the New Zealand Bill of Rights Act 1990 (BORA) (United Nations Human Rights, 2015b).

In regards to prisoners' rights, BORA affirms New Zealand's obligations under the International Convention on Civil and Political Rights and emphasizes New Zealand's formal commitment to fundamental civil and political rights. By defining these rights the national States are then able to define the prisoners' capabilities and introduce the required rehabilitation.

But this law is superseded by many other Acts and the UN Committee against Torture (2009:4) has expressed concern that the New Zealand Bill of Rights Act 1990 is not a supreme law that takes higher status than other domestic law.

A senior New Zealand lawyer recently advised in conversation with the writer that BORA carries minimal weight and it is better to apply the Convention on the Rights of Persons with Disabilities in legal debates in New Zealand rather than this national law.

Even though this legal advice indicates that BORA is weak it is still one of the legal instruments, albeit blunt, that needs to be applied in New Zealand when a prisoner is endeavouring to access disability support so they can realise their full capabilities, both when incarcerated and after release from prison.

2.10.1 The United Nations Convention on the Rights of Persons with Disabilities (CRPD) (United Nations, 2006)

This "[c]onvention is intended as a human rights instrument with an explicit, social development dimension. It adopts a broad categorization of persons with disabilities and reaffirms that all persons with all types of disabilities must enjoy all human rights and fundamental freedoms…It clarifies and qualifies how all categories of rights apply to persons with disabilities and identifies areas where adaptations have to be made for persons with disabilities to effectively exercise their rights and areas where their rights have been violated and where protection of rights must be reinforced" (United Nations, 2006).

The CRPD was ratified by the New Zealand Government on 26 September 2008 and enacted in New Zealand law through the New Zealand Bill of Rights Act (BORA). This means that New Zealanders with disabilities have the same rights as citizens without disabilities as the CRPD has been developed to specifically uphold the rights for people with disabilities as defined in the Universal Declaration of Human Rights.

But the New Zealand Government has not signed or ratified the Optional Protocol (OP) to the Convention on the Rights of Persons with Disabilities (United Nations, 2006). "The

importance of the Optional Protocol is because it establishes an ***individual*** complaints mechanism for the Convention …and also accepts individual rights on economic, social and cultural rights…. As well, the UN Committee on the CRPD who would hear the complaint can request information from and make recommendations to a party. The Committee may also consider and report on systemic or grave violations" (United Nations, 2006).

To circumnavigate the inability to use the OP to lodge a complaint with the UN Committee on the CRPD, and to ensure the capabilities of people with hearing loss are able to be fully realised, the Foundation has recently been granted full voting membership in the International Federation of Hard of Hearing Persons (IFHOH) (International Federation of Hard of Hearing People, 2014).

IFHOH has a membership of over 40 countries which meets at Congress once every two years and is currently working to achieve status with WHO and the United Nations.

IFHOH has membership in the International Disability Alliance (IDA) which is an organisation that "works to mainstream the rights of persons with disabilities throughout the United Nations system and with other global stakeholders to promote the UN Convention on the Rights of Persons with Disabilities, as a human rights treaty, and also as a social development tool" (International Disability Alliance, 2011).

This includes work towards the Conference of States Parties to the UN Convention on the Rights of Persons with Disabilities (CRPD), the CRPD Committee and other UN treaty bodies, the Human Rights Council and its Universal Periodic Review, the UN Special Procedures, the UN General Assembly, UN agencies like OHCHR[1], ILO[2], UNICEF[3], UNDESA[4], UNHCR[5], WHO[6], UNDP[7], as well as the Inter-Agency Support Group to the CRPD.

Even though the New Zealand Government has declined to sign the CRPD Optional Protocol, because the Foundation is an IFHOH member and IFHOH is a member of IDA,

[1] Office of the High Commissioner for Human Rights;

[2] International Labour Organisation

[3] United Nations Childrens Fund

[4] United Nations Department of Economic and Social Affairs

[5] United Nations Commissioner for Refugees

[6] World Health Organisation

[7] United Nations Development Programme

through IDA the writer was able to speak with two members of the UN Committee on the CRPD, one in person and one by email, raising various accessibility issues in New Zealand for people who are hard of hearing.

Another avenue available for citizens to raise concerns through is the United Nations Universal Periodic Review (UN UPR) (United Nations Human Rights, 2015c) of New Zealand which occurred in January 2014. In the UN UPR process submissions are made to the Chief Human Rights Commissioner by the New Zealand Government, the New Zealand Human Rights Commission and various NGO's working to address human rights breaches in New Zealand.

The Foundation worked with the Equal Justice Pilot Programme from the Faculty of Law, University of Auckland to prepare and submit on the following concerns as they impacted on people with hearing loss in New Zealand:

(a) access to insurance funded hearing aids for people with industrial noise injury;

(b) the lack of a State law mandating the provision of captioning enabling people who are hard of hearing to enjoy television, movies and other forms of visual communication to the same extent as their hearing able peers and

(c) the plight of children with Auditory Processing Disorder in New Zealand.

International oversight is very important in a country such as New Zealand as we are small and geographically isolated and because we have limited ability, as citizens, to influence change. Fortunately, our Government is sensitive to international criticism from the United Nations.

2.10.2 Application of the CRPD with Prisoners who have Hearing Loss

CRPD Article 14 addresses the liberty and security of the person. The UN is revising standard rules on imprisonment, which will enable further development of this Article in terms of prisoners with disabilities.

The Convention's obligations are incorporated into New Zealand's Disability Strategy. These rights have been outlined by the New Zealand Office for Disability Issues (ODI) (Office for Disability Issues, 2015b) as:

> "- Appropriate support in areas such as health and treatment needs, transport and access to visitors

- Referrals to appropriate external agencies in the community if needs cannot be met within the prison environment

- Their health and disability needs assessed on reception to prison by health services staff

- Transport and escort arrangements modified as necessary

- Additional visits from family and support agencies in addition to prisoner minimum entitlements of one private visitor per week."

Evidently the CRPD supports a prisoner who is hard of hearing having full access to hearing rehabilitation and the New Zealand prison authorities will be advised of this through autoenthnographic advocacy appeals to the Ministers of Health and Corrections, thereby ensuring State visibility of the need to support prisoners' human capabilities at the highest level of Government.

In conclusion to this in-depth examination of the various legal and human rights instruments and pathways it is evident that prisoner access to health care e.g. hearing screening, is permitted by UN convention and in New Zealand law. It is equally evident that some policies and processes are in place but access is not occurring due to Corrections failing to identify when a prisoner has a hearing loss.

In regards to prisoner communication support, prisoners who are hard of hearing are also legally permitted to access support at hearings through the provision of captioning or re-speaking for face reading purposes but this is probably not occurring for many who are hard of hearing as their hearing loss is unrecognised. This is a serious concern as it is denying prisoners with hearing loss full access to the legal system. Accordingly, they may not be able to fully understand the reasoning behind the judicial decisions, the sentencing process and outcomes and, as well, probation hearings.

In contrast, prisoners who are Deaf and use sign language to communicate are far more visible and it is written in Court policy that access to interpreters is supported.

Though invisible from the day to day consciousness of the general public, and unheard as they may be, prisoners with hearing loss have the same rights as all other citizens with disability to communicate to the best of their ability with the support they require being available to enable this, whether it be hearing aids; remote microphones; sign language, captioning, voice over, loops systems, cochlear implants etc.

But in New Zealand prisons they cannot as their hearing disability is frequently unrecognised and as a direct consequence they are further marginalised and their right to

participate in the judicial process is hindered and limited in application too. The negative ramifications of having an unrecognised and non-remediated hearing loss can be profound and lifelong. But with many prisoners hearing loss is only one area of need, albeit it is significant and far reaching, and they will require recognition of all issues impacting negatively on their ability to achieve social integration.

3

RESEARCH DESIGN AND METHODS: CHANGE FOR GOOD

3.1 Multi-method Qualitative Research

Having walked in both the hearing and hearing loss worlds, the writer is now an ethnographic researcher coordinating **multi-method** qualitative research. Whilst enquiring about the situation of prisoners with hearing loss, elements of auto and administrative ethnography and objective and subjective participatory action research were evidenced throughout which made it both a complex and pragmatic research exercise. Participatory action research is one approach that challenges the monopoly of knowledge and power that policy makers hold (Ulrich, 1996/2014, p. 95).

The writer decided to approach the area of concern using the mixed, multi-method complementary approach combining an auto ethnographic approach with participatory action research and normative policy design because of her lived experience as an advocate, professional CEO and an individual with the lived experience of hearing loss.

Normative policy design was defined by Laswell in 1936 who described the empirical and normative policy tradition through a prescriptive and normative seven-stage policy process model defined as “intelligence, promotion, prescription, invocation, application, termination and appraisal”….[Following on, f]urther stages were defined by Brewer and deLeon (1983), May and Wildavsky (1978), Anderson (1975), and Jenkins (1978) (Werner, J. et al 2007). Now the chronology of a policy process can be viewed as agenda-setting, policy formulation, decision making, implementation…evaluation …and termination (Fischer, F., et al, 2007 p. 43). This is known as the policy centric model which was used to underscore the development of policy centric thinking (Araral et al 2012 p. 222). This defines that policy implementation is essentially action and decision and aligns with the commitment to deliver on the normative policy recommendations.

“An understanding of values, or a normative inquiry, is a prerequisite to performing the task of policy design and evaluation” (Araral et al 2012 p. 94) and when policy failures occur an underlying cause can be that policy solutions have been developed without knowing the local conditions, including the human condition and nature. Ethnographic

research design can avoid this as a cause of policy failure because the human side of research is actively sought and included when policy issue identification is being applied.

Ethnography will now be examined both conceptually and as it applies to this body of work, followed then by a discourse on participatory action research and how both objective and subjective elements were applied to ensure this research continued to be outcome and impact focused.

3.2 Auto-ethnography

Ethnography is described as “writing about other people” (Erikson; 2011, p.45) and autoethnography is defined by Ellington (2011, p 599) as “research, writing, story, and method”, all of which form a bridge to connect social, political and cultural to the autobiographical. It enables the in-depth study of “a culture or phenomenon of which one is a part, integrated with relational and personal experiences”.

Through auto-ethnography the writer has challenged government policies in a number of areas, including health, disability, policing and justice [redacted] This paragraph has been removed due to confidentiality.

Auto-ethnography is a positive and empowering tool to use as it allows those affected by government policies to analyse the relevant policy; study its impact on the group the auto-ethnographer primarily culturally identifies with and then develop an academic, well-researched evidence based report on the issue with recommendations on how to address it. In effect, by applying auto-ethnography a consumer ensures the language of the bureaucrats is being used to define; report and advocate about the issue and the need to either develop or change policy to address it.

This can be challenging for policy developers as it moves the consumer identity and culture from being that of a charity based case or a group of constituents who are perceived by bureaucrats as whining to one of being an intelligent, capable, thinking group who are their peers and require acknowledgement.

When being applied auto-ethnographic writings can cause quite a high level of discomfort for policy makers (Fetterman, 2010, p. 131) who are contending with the impact of their bureaucratic decision making and it is not surprising that some would respond with claims of narcissism and post-modern excess as they may be challenged to move out of their comfort zones by issue identification done within this model.

In fact, auto ethnography is an important tool to ensure government policies are developed or improved to reflect the needs of those most affected by them and this writer uses it regularly to connect communities with government bureaucrats who develop the policies.

When doing auto-ethnography it is also very important to remain cognizant of the boundary critique as first introduced by Ulrich in 1996 and then used by Midgley et al in 1998 with the core idea being “that boundary judgments and values are intimately connected". This will define the information to be identified as relevant and who the people are that can generate it and “have a stake in the results of any attempts to improve the system” (Midgley, 2000, p. 136). Having defined the participatory action research model and framework of auto ethnography the writer will now describe instances of its successful application.

This section is written in the first person as I have effectively applied auto-ethnographic skills in response to the need to ensure my three children had their respective health and disability requirements funded by the New Zealand Government, their right to life respected and their capabilities of living a full and rewarding life supported to the fullest extent possible. Discourse on a number of other auto-ethnographic advocacy activities have been undertaken to address inequities. The writing will move back to the third person academic model when the auto-ethnographic reporting is complete.

When turning the lens on myself as a researcher I am mindful of being a wife of over 33 year’s duration; a mother and a grandmother. I am physically disabled with a mild peripheral hearing loss in conjunction with an Auditory Processing Disorder, which functionally impacts at the level of a moderate hearing loss. I also have familial Hypermobile Ehlers-Danlos Syndrome (HEDS) (Francomano, 2012) and inherited

Polyglandular Syndrome Type 111B and often use a hip brace and crutches or a wheelchair for mobility. Also, during the course of this research I have recovered from major surgery.

Professionally I am the Chief Executive Officer of the Foundation, which is a non-profit non-government national peak body that is charities registered, working with a small team (of up to 14 people) with a large mandate of representing people who are hard of hearing.

I am also Board member-at-large with human rights responsibilities for the International Federation of Hard of Hearing People (IFHOH – www.ifhoh.org) that has membership of over 40 Member Organisations globally. In this capacity I have been an Observer at meetings of the United Nations (UN) Committee on the Rights of Persons with Disabilities at the Palais Wilson, UN Geneva Headquarters in Switzerland.

In 2013 I attended an intensive training programme on the implementation of the Convention on the Rights of Persons with Disabilities (CRPD) at the International Disability Alliance in Geneva (IDA www.internationaldisabilityalliance.org/en).

Following this, I was the lead author, working with Dr. Ruth Warick, IFHOH President, in developing the IFHOH Human Rights Toolkit for the Implementation of the CRPD by the hard of hearing sector world-wide. The Toolkit was the knowledge base for a series of pilot Human Rights CRPD workshops being trialed in New Zealand and now IFHOH is in the process of implementing it through workshops being held globally thanks to a successful grant application from the Oticon Foundation, Denmark, as they granted US $130,000 to enable this.

In 2014, Human Rights CRPD implementation presentations were made by me to the following organisations: Acoustical Society New Zealand conference; Hear for Families New Zealand Annual General Meeting; Hearing Associations in New Zealand; the New Zealand Audiological Society conference; the World Audiology conference in Brisbane; the Centre for Deaf Education and Research Human Rights workshop in Vietnam and at the International Federation of Hard of Hearing People conference in Israel. The writer also met with the Board of the Deafness Forum of Australia to update them on the IFHOH Human Rights CRPD programme and was appointed to the New Zealand Ministries of Health and Education Auditory Processing Disorder Expert Reference Group with the Human Rights portfolio.

I was then invited in 2015 by IDA to contribute to a further week long session in Geneva, working collaboratively with the International Disability and Development Consortium (IDDC www.iddcconsortium.net) to develop a CRPD training module for implementing human rights for people with disabilities living in developing countries.

Also, I was the lead facilitator of two IFHOH Human Rights CRPD Workshops for representatives from mid and central European hard of hearing organisations held in Denmark in October 2015 and will also facilitate one IFHOH Human Rights CRPD Workshop for representatives from African and Asian hard of hearing organisations being held in New Zealand in January 2016. In all, thirty six representatives from organisations working with people who are hard of hearing or have tinnitus in Australia, Bangladesh, Belgium, Cambodia, Croatia, Czech Republic, Denmark, Estonia, Ethiopia, Finland, France, Germany, Hungary, Ireland, Kenya, Mongolia, Nepal, Netherlands, Norway, Poland, Slovenia, Sweden, Turkey, Uganda and the United Kingdom will attend these workshops. An IFHOH Human Rights CRPD workshop will also be held in the United States in mid-2016, which the writer will facilitate too.

In addition, and on behalf of IFHOH, I was invited to attend and contribute to the World Health Organisation (WHO) global ad-hoc consultation on the promotion of hearing care in Member States held during May 2015 in Geneva where participants were charged with defining a model ear and hearing care programme especially for use in developing countries.

Recently, in New Zealand, working with the Foundation Council and Board, I have successfully coordinated a campaign to raise NZ$130,000 to fund the development of research that will define the impact of hearing loss on the individual and the cost to the country. It is my intention to ensure that the needs and denied capabilities of the New Zealand prisoners who are hard of hearing are profiled in this research too.

As well, working with CEO and President of Deaf Aotearoa New Zealand (www.deaf.org.nz) and President of the Foundation, I have participated in meetings held over the last five years that have paved the way, after 28 years of significant disharmony, to the signing of a Memorandum of Understanding between the cultural linguistic Deaf community and the Hard of Hearing sector in New Zealand.

In addition, I am the chair of the New Zealand Captioning Working Group which is a national collaboration of the cultural linguistic Deaf community with the Hard of Hearing

sector, working together to achieve broadcast and internet captioning enabling access for people who are Deaf and Hard of Hearing across both imprisoned and general populations.

This Group introduced the New Zealand Captioning Awards, which are held annually to recognise captioning achievements in five different categories with the aim of positively acknowledging those who have done well and to encourage the New Zealand Government to legislate to enable broadcast access to people with all types of abilities. In 2015 the Minister for Broadcasting has agreed to present the top Award at this event.

Also, I am the co-creator and developer of the Silent Leadership Challenge (www.silentleadershipchallenge.com), which is an annual education and hearing loss prevention programme combined with on-line fundraising that supports the delivery of the advocacy and human rights work done by the Foundation in New Zealand.

This is an important event as it strives to educate corporate and community leaders on the impact of hearing loss and the needs of the hard of hearing sector and individuals living with it. WHO predicts that by 2050 one in four people worldwide will have some type of hearing loss and the Silent Leadership Challenge shows these change drivers that active intervention through public education is needed to turn back the tide and that they can make a difference by leading and being the change in their communities.

In 2014, 54 corporate and community leaders participated and in 2015, a further 51 participated and it has proven to be achieving the goal of educating change leaders as evidenced by the following narrative from Member of Parliament, Todd Muller who learned of the isolation and marginalisation that hearing loss causes when he did the Silent Leader Challenge.

> Would you rather be deaf or blind?" It's the sort of question you occasionally ask around a family breakfast table with your kids. Having initially thought that deafness would be an easier disability to manage, this week I took on the Silent Leadership Challenge where I undertook daily activities with a pair of very effective sound-silencing earmuffs, provided by the National Foundation for the Deaf. I found this experience both troubling and transformational. You are a part of a community, and yet separate – you can almost comprehend but not quite, despite the concentration, always scrambling to make sense of the quiet burbling.
>
> When I sat down at home in front of the television with my family, once the novelty wore off, I was stabbing-in-the-dark at working out what was happening. It was isolating.
>
> The next day I went to my office and tried to lead a team meeting with my staff. Initially it was quite comical, but now my staff have lost their voices and the office has ironically never

> been so quiet. My effectiveness is very limited, it has reinforced to me how much I take my hearing for granted and how hard it is for those who have lost it.
>
> It is worth taking the time to recognise the challenges that certain parts of our community face. I certainly recommend taking on the Silent Leadership Challenge as it may profoundly challenge many of your perceptions about daily life in the deaf community (www.sunlive.co.nz/blogs/8593-going-deaf-week.html).

As CEO of the Foundation, I am exposed to much that is occurring in the hard of hearing sector. Accordingly, as an auto-ethnographer, I "adopt[] a cultural lens to interpret observed behaviour, ensuring that the behaviours are placed in a culturally relevant and meaningful context…[and with an] open mind…explore rich, untapped sources of data not mapped out in the research design (Fetterman, 2010, p. 1).

Importantly, when undertaking action research I am "contributing to a stream of action and inquiry which aims to enhance the flourishing of human persons, their societies, communities and organizations and the wider ecology of which we are all a part" (Reason & Bradbury, 2001, p. 12).

By applying an ethnographic research design, my lived experience and personal perceptions as a person with hearing loss and medical challenges are added to this thesis, giving it a rich and colorful texture that would otherwise be absent if the value of the writer's views as an insider were unavailable or denied.

The ethnographic approach acknowledges that the relationship between the observed and the method of observation is entwined with valued judgments pervading even the most objective research. This is because "[p]eople act on their individual perceptions and those actions have real consequences – thus the subjective reality each individual sees is no less real than an objectively defined and measured reality" (Fetterman, 2010, p. 5). In respect of that, it is also vital to recognise that the "exact relationship between knowledge, language and reality is inherently unquantifiable…" (Midgley, 2000, p. 3) and our personal valued judgments will be as influential as evidence based facts.

In fairness, "there will be some problem situations in which hard system methodologies yield the most satisfactory results" (Jackson, 2000, p. 138) but there is a real need for flexibility in approach to ensure the most appropriate methodology is applied and for recognition by all researchers, whether working quantitatively or qualitatively, that they will personally impact on their research.

Having considered the researcher and the method of research, it is important to now consider the research subjects. Whilst working in the New Zealand non-profit sector and educating on human rights internationally I have frequently observed those who are disenfranchised, expressing cynicism and feelings of marginalisation, which are often compounded by government agencies being unable or unwilling to meet their needs.

There are multiple barriers obstructing appropriate policy development for people of perceived low social status who are marginalised, such as prisoners with hearing loss, and unless advocacy bodies take up the task of publicly advocating for policy development and implementation on their behalf, it is very unlikely that prisoners with hearing loss (a vulnerable high needs group), would ever have their needs appropriately recognised and addressed.

In considering the boundaries when looking at the issue of prisoners who are hard of hearing, “Churchman argues that as much information as possible should be “swept in” ” (Cordoba, Midgley, & Torres, 2000, p. 205) and in this research the perspectives of a wide variety of stakeholders will be sought to ensure all aspects of marginalisation are captured.

When setting the boundaries which are social or personal constructs that define the limits of the knowledge to be taken in my research it is important to identify the pertinent knowledge; the key people who generate this knowledge and to have a stake in the result of any attempts to improve the system (Midgley, 2000, p. 137).

Churchman (1979, pp. 9-10) and Cordoba, Midgley & Torres (2000, p. 205) stressed that pushing out the boundaries of analysis could broaden the boundaries of those who contribute, ensuring the opinions and views of stakeholders from a wide variety of perspectives are swept in. This would include the views of people suffering with issues of marginalisation.

Participatory action research will be applied in this ethnographic research because I am working within the context of both my professional career as an advocate and as an individual with the lived experience of having a communication disorder. Because of this contextual setting, as an ethnographic change agent I will pursue multiple streams of opportunity as will become evident in the methodology discourse.

Ethnography will now be examined both conceptually and as it applies to this body of work, followed then by a discourse on participatory action research and how both objective

and subjective elements were applied to ensure this research continued to be outcome focused.

3.3 Ethnography (Fetterman, 2010, p. 1)

The ethnographic approach has a life cycle starting at the pre-natal stage with the problem or issue being realised, which then leads to the gestation or birth stage when the research proposal is delivered. Following on will be the midwiving stage when external matters are addressed such as ethics committee applications being submitted and funding applications too.

Fetterman considered fieldwork preparation to be the childhood stage, which then led to adolescence or adulthood being the part of the life-cycle when the fieldwork is performed. Then when the research is done and the narrative is written, retirement and last rights will occur. This illuminating ethnographic life-cycle model will be applied to frame the research issue identification, development and delivery of this research.

3.4 Research Design

Usually, and sensibly, research design considerations are made prior to the research commencing. However, of necessity, the design for this research was undertaken in two parts, one before the research commenced and the other when iterative changes were made in response to changing policy opportunities.

“Critical to commencing observation and reflection is *noticing* – something pulls us up, is noticeable, remark-able” (Wadsworth, 2010, p. 52). This ‘ah-ha’ moment occurred when the writer was appalled by the information she read in the Bowers Report (Bowers, 1981).

Though the response was emotive it was also combined with the logical and practical perspective that something had to be done and without hesitation the writer began the task of identifying the current situation that prisoners with hearing loss were contending with and developing an evidence base for advocacy.

This emotional and practical experiential response will be understood when the writer details a wide range of auto-ethnographic experiences as a Carer and advocate and as a person who has experienced late onset disability.

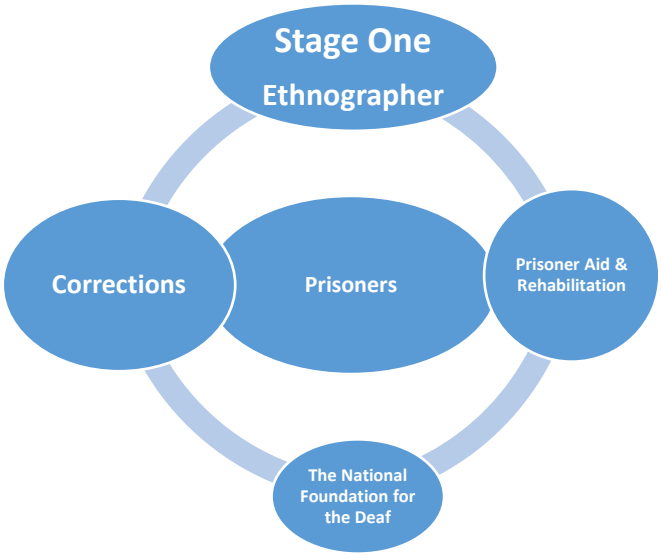
3.5 Participatory Action Research

The Bowers' report discovery then led to the development of qualitative research that would define if these recommendations were implemented and how they have addressed the prisoner loss of capabilities and the negative impact on their social status. The ethnographer has undertaken qualitative participatory action research to ensure the voices of those most affected by the various wicked issues are inter-wound throughout the research findings and resultant policy advice and recommendations to Government.

As outlined below in Figure 3.1 participants to be invited by the ethnographer to participate in Stage One of the initial research design were the Department of Corrections (Corrections), prisoners with hearing loss, The National Foundation for the Deaf (the Foundation) and the Prisoner Aid and Rehabilitation Society (PARS).

Research Design: Stage One – Invited Participants

Figure 3.1. Research Design, Stage One



Corrections presented as a significant barrier to the research progressing, as they declined the opportunity to participate and or fund the work of the Prisoner Aid and Rehabilitation Society interviewers who would be implementing the prisoner interview component of the research design. Surprisingly, Corrections also refused to accept funding from an external agency that the writer offered to source, which would enable the research to proceed. This showed that funding was not the issue and their negative attitude and lack of willingness as an institution to learn about the occurrence of hearing loss in their prisoner population

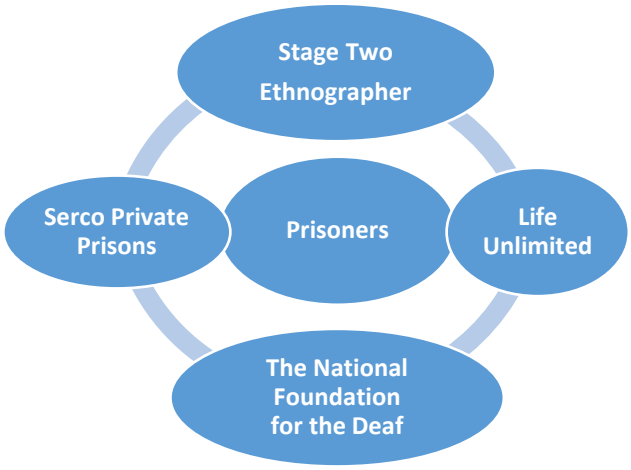
was the actual concern. This showed that Corrections itself presented as yet another barrier to prisoners with hearing loss being identified and offered hearing loss rehabilitation to support their reintegration at the end of their prison sentence.

When Corrections presented as a further barrier by declining the opportunity to participate it appeared that the research could not proceed. However, fortuitously, Mr. Steve Hall, the Serco Private Prisons Australasian Director for Recidivism Reduction, responded to an advertisement on the New Zealand Institute of Directors website from The National Foundation for the Deaf who were seeking to recruit two new voluntary Board Directors.

Mr. Hall met with the writer in her capacity as CEO of the Foundation and with the Foundation's Board of Directors. After discussions he determined that he did not wish to join the Foundation's Board but continued dialogue with the writer and an opportunity for the prisoners hearing loss research to continue seamlessly was identified. The research design was the same but instead of Corrections participating, Serco Private Prisons stepped up and agreed to provide support for the research to proceed.

Accordingly, the research design was repaved to include the **departure** of two key parties (Corrections and Prisoner Aid and Rehabilitation, PARS) and the **addition** of two new parties (Serco Private Prisons and Life Unlimited, Hearing Services). Please see Figures 3.1 and 3.2 to gain a visual outline on the identity of the participants in the two separate stages of this research design.

Figure 3.2. Research Design: Stage Two



As outlined above in Figure 3.2, the departure of Corrections and PARS from the research design permitted the addition of the two new parties, Serco Private Parties (www.serco.com) and Life Unlimited, Hearing Services (LUHS) (http://lifeunlimited.net.nz/hearing).

Mr. Hall recommended that the number of prisoners being hearing tested increase from 50 to 100, in line with the number that Bowers tested and advised he would manage the Serco Ethics Committee application development and approvals process.

This participatory action research presented as a vehicle for social change, which the writer has done successfully on a number of previous occasions when addressing professional and personal inequities, some of which are described in-depth further on in this chapter.

3.6 Autoenthnographic advocacy

3.6.1 Human Capabilities Approach

My husband and I parented three children, all of whom were born with a range of significant medical issues. All the way through the lives of our children we have endeavoured to support them to be what they were capable of being and to not accept the limitations placed on them by others, though at times this was incredibly difficult to achieve as there was much opposition.

For example, we were told that our eldest daughter who was born with the inability to make sufficient functional antibodies to adequately control a range of bacterial infections

was born to be raised in hospital and that she would not live longer than 10 years. But, we refused to believe this and she is now a post-doctoral research scientist, working internationally and fulfilling her life goals.

3.6.2 Autoenthnographic advocacy: Pediatric Sleep Apnea

Our son was born with the propensity to stop breathing and he regularly became quite cyanotic when asleep. It was very stressful and some nights after reminding him to breathe by either touching him or giving him mouth-to-mouth resuscitation I would dream of little white coffins.

This was a condition that he was supposed to have grown out of by the age of one. When he kept becoming cyanotic during sleep over the age of one year the medical staff caring for him were cynical, disbelieving and unsupportive. From this life experience, I knew that our son had to be supported to live a life worth living, far more so than any other person I have ever known and that we could not give up on him.

Our son learned to keep waking himself up to breathe and because he had to stay awake to remain adequately oxygenated, he became sleep deprived and would sometimes present as significantly developmentally delayed. When he was aged 7 years a doctor told us he believed our son was intellectually disabled but I knew the doctor was wrong as I had seen times when our son was intellectually lucid and very sharp.

Eventually, I became his advocacy ethnographer. I recorded a video of our son sleeping and going cyanotic because of low blood oxygenation levels and then gave the footage to a pediatrician in the New Zealand private health care sector to view.

He viewed it and then immediately contacted a sleep specialist in the adult public health service who reviewed the video and immediately placed our son on a Bi-pap ventilator when asleep. We then learned how to manage the use of this machine at home and we were told that he was the first child in New Zealand to leave hospital using a Bi-pap ventilator. This life-impacting medical condition was eventually recognised when, in desperation, yet again I became an ethnographer, recording the evidence in support of my role as my son’s advocate. After only 8 days on adequate ventilation overnight our son could dress himself, skate board and had begun to learn how to socially integrate. The change was profound.

By this stage we had learned to access alternative systems of pediatric healthcare to use when the State failed to adequately provide. Our son was fortunate in that he had competent and capable parents who upheld his human capabilities and right to life and his right to enjoy a quality of life at the same level as his peers. However, this level of autoenthnographic advocacy would not be available to many children living in families of a lower social status and the outcome for these children would be the loss of their human capabilities and either a shortened life-span or a life not worth living.

3.6.3 Ethnographic: Blood Safety Advocacy

As an infant and small child our eldest daughter required medical treatment for a wide range of infections and she was on 4 different types of antibiotics orally by the age of 4. Eventually it was recognised that the antibiotics were not holding back the onslaught of infections and she required immune gammaglobulin blood product infusions sourced from voluntary blood donors, that bought with it the risk of blood product contamination with AIDS, Hepatitis C and CJD.

She had to endure this treatment for 24 years to control overwhelming ear infections that became non-responsive to antibiotics and threatened the integrity of her brain and also caused early bronchiectic changes in her lungs.

There were a growing number of families in New Zealand who had children struggling with primary immune deficiency disorders like we were that were experiencing similar levels of medical neglect due to clinical ignorance.

Through reflecting on my personal experiences it is evident that I became an effective autoethnographic advocate for policy change on behalf of my family and as well, all of the other families who sought our support and assistance.

3.6.4 Autoenthnographic advocacy: Blood Products

To address this challenge my husband and I drove the development of a national organisation, namely Kids with Immune Deficiencies Foundation of New Zealand Inc. (KIDS), which provided a platform for participatory action research and driving social change through advocacy and education.

One notable participatory action research achievement through KIDS was a submission to the New Zealand Government Select Committee on Health in regards to proposed

changes to the Act covering the administration of blood products in New Zealand. The Bill proposed that administration charges were to be levied and paid for by recipients of blood products. We submitted that if this became law our family and many other families like ours would become homeless and, eventually, bankrupt as we would need to sell our assets to pay for the blood product infusions our children were receiving, to ensure they did not die of infection.

We were successful and the Hon Bill English, Chair of the Government Health Select Committee called to advise when this proposed Bill had been quashed. This was a collaboration of affected families who engaged in the political process and then achieved social justice. It underscored again how important it is that social change drivers gain a factual evidence base to work from. This positive outcome was achieved by participatory action research with health professionals and affected families who provided the information that was presented to the Government Select Committee by oral submission.

Another significant area of auto-autoenthnographic advocacy during that period was in the area of blood safety public policy when Creutzfeldt-Jakob Disease (CJD) emerged as a recognised low probability risk but a high-risk threat by being a potential invading pathogen in the national blood supply.

Because this was a wicked problem (Kingdon, 1993b, p. 44) I was asked by the Minister of Health, the Honourable Jenny Shipley, to be a Ministerial Special Advisor on blood safety and appointed as an additional consumer representative, alongside my colleague from the New Zealand Haemophilia Society, to the Ministry of Health Blood Safety Committee.

To understand a problem, knowledge of all aspects of the issue is required ahead of time as “problem understanding and problem resolution are concomitant to each other” (Rittel & Webber, 1973, p. 161). Rittel advises “the one-best answer is possible with tame problems, but not with wicked ones” as it has no criteria to define when a solution has been found other than they are identified as good or bad or better or worse and unfortunately there is no ultimate test of any solution, thus we are only offered a one-shot opportunity to address the problem.

This was exactly the situation with the risk of CJD prions possibly infecting the national blood supply, as we had to contend with developing the best policy possible whilst recognising that the scientific knowledge on how the prion infected the blood supply was

still relatively unidentified and that no matter what we did or recommended the problem was not solved.

Also, the issue of New Zealand's public policy response to the risk of CJD contaminating the national blood supply was an example of how a policy window opens when an issue or problem suddenly rises to the national arena. The Minister of the Crown with the portfolio where this issue sat was politically impacted by a very significant voter backlash which became evident through news media and television reports. This was recognizable as an emerging political stream which in turn, rather desperately required a proposal or way to contain the problem and thus the policy stream became evident (Kingdon, 1993a, pp. 40-43).

National policy had to be developed in regards to CJD and blood safety and I was appointed to the group of five people who defined the risk and the response to the threat. I had a sharp learning curve on brain autopsies and processes for developing and ensuring the safety of all blood products from CJD whilst regularly taking my young daughter and son into hospital for blood product infusions!

It was a most unusual and at times terrifying situation as, in some respects, it was like being on a runaway train but, as a parent, I had to stay on board to ensure my children received the best health care possible to enable them to have lives worth living. It was also a further episode of participatory action research as our sector was one that was severely impacted and we had to participate to ensure the policy developed was the most robust and safe for our family members.

I have since been advised by the New Zealand Ministry of Health that the policy as developed was picked up a couple of years later by the Australian Therapeutic Goods Authority and applied as Australian CJD risk amelioration policy for their blood supply too. From this experience I learned to have advocacy responses prepared so I was poised and able to take advantage of policy windows as they opened.

At the time I was doing this work I was asked if I would stand as a Member of Parliament, but I declined as my children's needs had to come first. Also, then, and now, I recognise the need to be politically neutral to be able to effectively drive social change through participatory action research.

3.6.5 Ethnography: Carer Respite

Another significant area of policy I was involved in at this time was the need for health authorities to implement respite for families caring for high needs medically fragile children at home.

During the winter months when our two older children would inevitably develop respiratory infections, my husband and I would run their two intravenous lines at home overnight, giving them both intravenous antibiotics; nebulize them both regularly overnight and also ensure our son's ventilator kept running uninterrupted whilst he slept.

Then, every morning we would all go off to work and school as if what had occurred over the previous night was entirely usual. We functioned very much from the perspective that this was normal [redacted] This paragraph has been removed due to confidentiality.

[redacted] This paragraph has been removed due to confidentiality.

[redacted] This paragraph has been removed due to confidentiality.

At the same time there was a solo mother living locally in New Zealand who was single-handedly raising a daughter with severe autism and after many months without respite she killed her daughter and was convicted of manslaughter.

Though incredibly sad, this mother's action ensured a policy window opened. As a result, working with the Ministry of Health's Clinical Director Dr. Colin Feek I developed a questionnaire that was distributed to twenty-three consumer organisations working with families caring for children with significant medical conditions with the aim of defining carer respite needs.

All twenty-three consumer organisations completed and returned the questionnaire and the outcome was that they identified a triage system for identification of the respite care needs for families caring for children who were medically fragile and the Government dedicated NZ$750,000 to a family respite programme called Family Options. This was a programme that was entirely designed by the parents and caregivers working with their consumer organisations.

This enabled funding of respite for families living and caring for the top 50 highest needs medically fragile children in the Northern region of New Zealand. I recently learned this programme has now been expanded to accommodate 100 children. This too was a collaboration of affected families who engaged in the political process and then achieved social justice, which has been delivering respite to families for over 16 years as a result.

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We were displaced from our recognised social structure, instead becoming marginalised and eventually joining forces with a group of other families who were also struggling to ensure their children realised the human capability of a life worth living.

[redacted]
This paragraph has been removed due to confidentiality.

Accordingly, we were not afraid to ask the hard questions, which caused angst for some of the health care professionals involved in the care of our children.

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[redacted] This paragraph has been removed due to confidentiality.

As parents, we worked from the approach of actively supporting what our children were able to do and what they told us they wanted to be and we supported them to achieve their life goals. Our decision and choice to do this have been validated many times over as we now observe our three adult off-spring, all of whom are tertiary qualified and are successfully employed, living life to the full and as well, we have a healthy grandchild.

3.6.6 Auto Ethnography on learning, lobbying and shaping policy in New Zealand through the school of lived experience

When our eldest daughter was 4 years of age my extended family was blood tested to check for bone marrow donor compatibility as consideration was being given to offering her a bone marrow transplant. From that experience, my first formal foray into participatory action research occurred. This was done which was in response to the plight of families, some of whom were being offered bone marrow transplants for their babies and children who had severe primary genetic immune deficiency disorders[8]. As a result of this, participatory action research was done, I used the auto ethnographic questionnaire

[8] The families were understandably desperate to save the lives of their babies and children but they were frequently unable to cope financially with the costs of spending months at the only national paediatric hospital in New Zealand and then after transplant setting up their homes for their infants when they were discharged. This report, which as ethnographer I developed using the participatory action research model, by seeking the family responses to a set of questions, underscored the need for government to approve eligibility for the Handicapped Childs Allowance for caregivers of children living with all types of primary immunodeficiency disorders. The issue was then raised with our Member of Parliament who had our eligibility to receive the Allowance raised as a question in the New Zealand House of Representatives (Parliament) Debating Chamber. As a consequence, the Handicapped Childs Allowance was then formally granted by Parliament to families raising children with Primary Immunodeficiency Disorders, including my own family.

This was a collaboration of affected families who engaged in the political process and then achieved social justice. It clearly showed the Writer how participatory action research and ethnographic questionnaires can shape positive engagement with decision makers, enabling them to use the evidence provided to change the life outcome for families like ours. It was a very powerful learning experience that underscored why I have repeatedly used this model of research to good effect.

method with the affected families, who gave freely of their knowledge, and a strong evidence base was developed for the submission we made to our local Member of Parliament.

As can be seen, when considering the work done for families with children requiring bone marrow transplants and as will be done with the prisoner research, the intention is to positively change their situations and to improve their lives[9]. These examples align with the notion that participatory action research (PAR) "is the sum of its individual terms…[with] all people in a particular context ...involved in the whole of the project undertaken. Action is interwoven into the process because change, from a situation of injustice toward envisioning and enacting a "better" life…is a primary goal of the work…. PAR is distinct in its focus on collaboration, political engagement, and an explicit commitment to social justice" (Brydon-Miller, Kral, Maguire, Noffke, & Sabhlok, 2011).

These experiences shaped the auto-ethnographic participatory action research design as it empowered all of us who contributed and when we succeeded we were able to hold our heads up high even though our personal burdens remained significant. We were able to take back some of our power and lost status through the action of lobbying that resulted from reflecting on personal issues and applying auto-ethnography to raise awareness of shared public issues.

3.6.7 Auto Ethnographic reflection on shaping policy internationally

Because of the shortcomings of the health care available for our children in New Zealand we recognised the significance of international knowledge as that was not only keeping our children alive, it also offered them the quality of life that we as their parents so wanted

[9] [redacted]

This paragraph has been removed due to confidentiality.

We evidenced that children with disabilities, whether physical and or medical, are shunned by society or at least kept at a distance, presumably because they are unable to contribute back to society to the level expected and required.

them to realise. Accordingly, we led the way forward on achieving the change required to ensure this occurred.

I became one of the founding Board members of the International Patient Organisation for Primary Immunodeficiencies (IPOPI) and attended its inaugural meeting in England, staying for a week at Keble College, Oxford University. This was funded by a grant from the New Zealand Government Minister of Internal Affairs.

It was a life-altering meeting because it broke down the barriers that the geographical and emotional isolation of having children with such rare medical challenges created. It showed how the strength of parents from across the globe, working collaboratively, could dramatically improve the quality of life for many thousands of children. We were empowered global change drivers!

3.6.8 Auto Ethnography on lobbying

The IPOPI Board members were all early adopters of email and during my tenure as Chairperson we established a programme for the donation and delivery of gammaglobulin blood products for children with primary immune deficiency disorders living in Chile, New Belgrade and India.

I would coordinate this work by email overnight from my home in New Zealand whilst monitoring our son to ensure he was adequately ventilated when asleep. In particular, I worked with the IPOPI Deputy Chairperson who was based in Italy. Between us we ensured the children in New Belgrade could receive much needed infusions of gammaglobulin as the American Red Cross permitted the product to be taken through the American Army blockade to a mother who kept the blood product in a locked fridge at the airport. This enabled the children who had primary immunodeficiency who were living in New Belgrade during the civil war to have a life worth living.

As can be seen, I had a full and active life with many responsibilities and duties, which was then dramatically altered when, at the age of 39, my hearing, eyesight and balance were injured. After ensuring the work of providing the blood products to the children in Chile, New Belgrade and India would continue in the very capable hands of the IPOPI Deputy Chairperson I withdrew from all national and international commitments and over a period of 3 years I recovered lost capabilities and rehabilitated for those unable to be recovered.

During this time, I commenced university studies in law, alternative dispute resolution, public policy and management whilst learning how to wear and use hearing aids with FM receivers, how to manage vestibular damage causing balance challenges and the occurrence of a visual spatial malfunction. I also endured a significant transition from being a fully functional member of the society of the hearing abled to being a fringe dwelling observer living with hearing loss who needed to learn a new way of communicating and gaining and maintaining social integration.

From this experience, I learned of the need for advocacy by people with hearing loss and now apply my skills to ensuring the rights and needs of people who have hearing loss are raised and their capabilities addressed. At this point, the auto-ethnographic reporting now moves back from the first person to the third person academic model.

3.7 Fetterman's Ethnography applied to the Issue of Prisoners with Hearing Loss in New Zealand Prisons

This issue will now be framed through the ethnographic research model with stages of prenatal care where the issue is considered; the stage of gestation and birth where the research proposal is outlined, the midwiving stage where the external environment and matters such as ethics approval are attended to; the adolescent and adult stage of fieldwork and the retirement and last rites are completed when the research is completed and being closed down. In addition, a life-cycle disruption stage with twin presentation will be examined.

3.7.1 Fetterman's Pre-natal care: The Problem and Considerations (Fetterman, 2010, p. 140)

As the writer is a professional advocate for people with hearing loss, New Zealanders who are hard of hearing and powerless to change a particular set of circumstances often seek her assistance and intervention.

But that is not the situation for prisoners who are hard of hearing as this research issue was not raised by a prisoner or their family. Instead it was detailed by Bowers over 30 years earlier through her lens as a clinical audiologist and researcher and the writer is now revisiting it and viewing it through the lens of a social public policy researcher.

Though typically the problem or issue shapes the research design, in this instance there are two significant drivers dictating the type or model of research to be applied. The first consideration is a need to understand, through research, if Bowers recommendations were

implemented and the second consideration is the necessity to accommodate the researcher's range of different abilities. Both considerations will now be examined further.

The first design consideration is to define whether the Bowers Report recommendations were applied. She recommended that hearing loss in prisoners be detected and managed by Corrections and that paediatric hearing loss be detected and rehabilitated in New Zealand.

Therefore, it is important to define in this research design whether programs have been implemented by the Government for the prevention, identification and treatment of ear disease in children as early intervention may reap lifelong benefits.

To research whether Corrections is identifying and rehabilitating hearing loss in prisoners, a questionnaire will be developed and submitted for completion by their senior management and policy staff working in the prisoner health area. Initially the request to complete the questionnaire will be done and discussed in as many meetings as necessary with a range of Corrections staff and then followed up by emailed correspondence.

Then, to identify the hearing loss rehabilitation programs available to the non-incarcerated hard of hearing sector and to understand if they are available to the prisoners with hearing loss incarcerated in New Zealand prisons, a questionnaire will be developed and submitted for completion by the Ministry of Health Disability Support Services hearing programme manager.

The driving reason behind the need to have a large component of the research information provided through questionnaires is explained as follows.

The ethnographic research design by questionnaire is introduced to accommodate the hearing capabilities of both the ethnographic researcher and the prisoners. As the prisoners are self-referring they are most likely hard of hearing as is the researcher and it is important and highly preferable that the research raw data and information from the prisoners be in written format to reduce the risk of communication errors caused through reduced hearing.

Also, as the ethnographer is physically disabled and more vulnerable to falls and at greater risk of physical harm, it is not appropriate, for personal safety reasons that she meet alone with prisoners to ask questions, some of which may be sensitive. It is important that the people who support the prisoners to answer the questionnaire are physically able

to defend themselves as the questions being asked could cause emotional responses and distress. This is because there may be a history of child neglect involved with long term untreated ear disease that could cause the prisoner to become emotionally responsive.

To accommodate this, Prisoner Aid and Rehabilitation Services (PARS) which is an organisation contracted by Corrections to interview prisoners prior to their release from prison to define their post-release support requirements, will be asked to support the 50 randomly selected prisoners to complete the questionnaire developed by the writer immediately after they have completed their pre-release interview with them.

Then, when the 50 prisoner questionnaires have been completed, the PARS staff who supported the prisoners to complete the questionnaires will be asked to complete a questionnaire on their experience of doing this, enabling the ethnographer to explore the PARS staff bias and influence of the prisoners when the inmates were answering their questionnaires.

Having defined the problem being researched the next research life stage defined by Fetterman (2010),for consideration is gestation and birth: The Proposal.

3.7.2 Fetterman's Gestation and Birth: The Proposal (Fetterman, 2010, p. 141)

In the ethnographic research proposal stage the research data, which outlines the information required by funders, supervisors and all other parties, is prepared. It is imperative that this stage be done accurately as the data will be used to support the delivery of all following stages of the ethnographic research lifecycle.

During this stage the four questionnaires, namely the Prisoner Questionnaire; the Ministry of Health Questionnaire; the Department of Corrections Questionnaire and the PARS Staff Questionnaire will be conceptually defined.

This is a time-consuming stage with the expectation that a number of questionnaire iterations will need to be developed to ensure the questions being asked will elicit responses which are informative to the purpose of the research. Also it is imperative that the questionnaires are written to accommodate the minimum literacy capabilities of those answering the questionnaires.

The questionnaire templates are now outlined with general comment about their design outlined beneath each table.

Table 3.1. Questionnaire One: Prisoners with Hearing Loss

Section One: Prisoner Hearing Loss Questionnaire

	Please circle: O
1. What level of high school did you reach? Please circle:	Before Year 12 After Year 12
Score 1 point if before Form 6 (Year 12)	----------
2. Have you ever had deafness or trouble hearing with one or both ears? If yes go to question 3, if no please go question 4.	Yes No
1 point scored for this question	----------
3. Did you ever see a doctor about your hearing problems?	Yes No
If Yes score 2 points for this question	----------
4. Without a hearing aid, can you usually hear and understand what a person says without seeing his/her face if that person whispers to you from across the room?	Yes No
If Yes score 1 point for this question	----------
5. Without a hearing aid, can you usually hear and understand what a person says without seeing his/her face if that person talks in a normal voice to you from across the room?	Yes No
If Yes score 1 point for this question	----------
Points Total:	

Questionnaire Responses scoring 3 or more

- If a Prisoner scores 3 or higher on Section One of this Questionnaire please ask them to complete the following two sections of this questionnaire.
- If a Prisoner scores 3 or higher on Section One of this Questionnaire please refer them to the Medical Officer for further assessment.

Table 3.2. Section Two: Prisoner Hearing Loss Questionnaire

Q2a. Did you find it difficult to learn maths at school? Q2b. Did you find it difficult to learn reading or writing at school?	Please circle: O Yes No Yes No
Q2c. Do you wear a hearing aid? If yes, do you wear 1 or 2 hearing aids?	Please circle: O Yes No 1 2
Q2d. Did you know you had problems with your hearing before you went to prison?	Please circle: O Yes No
Q2e. If yes, did you wear hearing aids before going to prison?	Please circle: O Yes No
Q2f. If yes, did you have your hearing aids with you in prison?	Please circle: O Yes No
Q2g. a. Did you use your hearing aids in prison? b. If not, why didn't you use them? Please explain:	Please circle: O Yes No
Q2h. Do you communicate using New Zealand Sign Language?	Please circle: O Yes No

Table 3.3. Section Three: Prisoner Hearing Loss Questionnaire

Q3a. Have you served a sentence in a New Zealand prison?	Please circle: O Yes No
Q3b. Have you done at least three months in prison at one time?	Please circle: O Yes No

Q3c. Your gender:	
Male	
Female	
Prefer not to say	
Q3e. Which area do you live in or what Iwi do you identify with?	
Northland	
Auckland	
Waikato	
Bay of Plenty	
Gisborne	
Hawke's Bay	
Taranaki	
Manawatu-Wanganui	
Wellington	
Tasman	
Nelson	
Marlborough	
West Coast	
Canterbury	
Otago	
Southland	
Other (please specify):	
Q3f. What is your preferred ethnicity?	
Asian	
European	
Maori	
Pacific Island	
Prefer not to say	
Other (please specify):	

Q3d. Your age:	
18-29	
30-44	
45-59	
60-69	
70 plus	

It is also at this stage that it was identified the proposed research design would include 50 male prisoners, currently in an Auckland prison, from all ethnicities being recruited with no restriction on whether they are New Zealand citizens or not; the age group is open; self-selection for hearing screen will be done and their term of imprisonment needs, if at all possible, to be a minimum of three months for reasons of availability for follow up, as required as prisoners are often a transient population by nature which means it may be difficult to locate them after release.

The questionnaire construct and language content will also be reviewed by a teacher of adult literacy to ensure the language is at a level that it will be understood by the general prison population and the sentence structure is appropriate for this audience too.

Questionnaire Two

The second questionnaire was for completion by the prisoner interviewers from PARS however it became evident early on that this step was unable to be implemented therefore the questionnaire template was not developed.

Table 3.4. Questionnaire Three: New Zealand Department of Corrections

The third questionnaire template to be developed is that to be completed by the Director for Prisoner Health at Corrections. The aim of this questionnaire is to clarify how hearing loss in prisoners is identified; the rehabilitation programme and what communication support structures are in place enabling access to justice for both Deaf and Hard of Hearing prison populations.

Corrections Policy Identification: Hearing Loss in Prisoners

Q1. What is the NZ Department of Corrections policy on providing hearing testing for prisoners on remand?	
Q2. What is the NZ Department of Corrections policy on providing hearing testing for prisoners on sentencing?	
Q3. How many prisoners (as at February 1, 2011) have clinically confirmed hearing loss?	
Q3a. Another type of communication disorder which has recently been proven to respond, in some instances to the use of hearing aids and/or FM technology is a condition known as auditory processing disorders (APD). How many prisoners have APD?	
Q4. Do rehabilitation programmes in New Zealand prisons now include:	
Q4a. Recognition of hearing loss? If yes, please explain how this is structured:	
Q4b. Treatment of ear disease and hearing loss? If yes, please explain how this is structured and delivered:	
Q5. If a prisoner complains of having a hearing loss how is this managed?	
Q6. If a prisoner is recommended by a clinician as requiring hearing aids how are these funded?	
Q7a. If a prisoner is diagnosed as having a hearing loss what rehabilitation is offered?	
Q7b. Are they offered the opportunity to learn New Zealand Sign Language? Yes or No – please circle	
Q8. If a primary type of communication for a prisoner is New Zealand Sign Language how is this accommodated in the New Zealand prison system? Please advise:	

Table 3.5. Questionnaire Four: New Zealand Ministry of Health

Questionnaire Four is intended for completion by the Disability Support Services staff of the New Zealand Ministry of Health. Their responses will help clarify the Ministry of Health policy in regards to identifying and offering rehabilitation to prisoners with hearing loss. Their response will need to be viewed in line with New Zealand's obligations in the application of the United Nations Convention on the Rights of Persons with Disabilities as expressed through the New Zealand Bill of Rights.

Policy Identification: Management of Hearing Loss in Prisoners

Q1.	Screening for Hearing Loss
a)	At what age/s is hearing screening done in New Zealand?
b)	Is hearing screening mandatory in New Zealand?
Q2.	What is the Ministry of Health Policy on funding of:
a)	Hearing loss prevention programmes? Please advise:
b)	Rehabilitation for people with hearing loss? Please advise:
Q3.	How much does the Ministry of Health spend on:
a)	Hearing loss prevention programmes? Please advise:
b)	Detection and diagnosis of hearing loss (cost by Programme). Please advise:
c)	Rehabilitation for people with hearing loss? Please advise:
Q4.	Who is responsible for the delivery of Ministry of Health funded hearing loss rehabilitation services to prisoners? Please advise:
Q5.	Is there a process whereby the Ministry of Health and the Department of Corrections communicate to identify the annual rehabilitation needs for prisoners with disabilities, in particular prisoners with hearing loss? Please advise:
Q6.	Who audits the delivery of the Ministry of Health contracted hearing loss rehabilitation for prisoners? Please advise:
Q7.	How many people, in total, use the Ministry of Health funded hearing disability rehabilitation services? Please advise:

3.7.3 Fetterman's Ethnographic Midwiving: External Matters (Fetterman, 2010, p. 141)

The ethnographic midwiving stage is defined as being when a group or a panel of administrators and researchers considers the research proposal from the perspective of the ethics of working with living beings and ensure that the safety and well-being of the research subjects is appropriately considered in the research design. In effect, this is the change being started.

At the midwiving or post natal stage of this research design the application for approval of social or behavioural research involving human subjects will first be submitted to the Flinders University, South Australia, Social and Behavioural Research Ethics Committee and when their provisional consent is given, then further submitted to the New Zealand Department of Corrections Ethics Committee.

The three questionnaires, carefully structured as outlined in the birthing stage of the research design life cycle, will ensure relevant policy discovery occurs from the prisoners, Corrections and the Ministry of Health. The intention is that all three questionnaires will be submitted, with the completed Ethics Application form to the Flinders University and Southern Area Health Service Social and Behavioural Research Ethics Committee.

When approval to proceed is given by Flinders University and Southern Area Health Service Social and Behavioural Research Ethics Committee an application to do the research will then be submitted to the New Zealand Department of Corrections Strategic Analysis and Research team who managed the process for applications to the Corrections Ethics Committee. They too will want copies of the Prisoner, Corrections and Ministry of Health questionnaires included with the application and proof of approval from the Ethics approval from Flinders University and Southern Area Health Service Social and Behavioural Research Ethics Committee.

This is because it is their duty to protect the interests of prisoners as human research subjects and to analyse if the research will meet the strategic aim of Corrections, which is "Improving public safety by ensuring sentence compliance and reducing re-offending, through capable staff and effective partnerships".

3.7.4 Fetterman's Ethnographic Childhood: Field Work Preparatory Stage (Fetterman, 2010, p. 142)

This is an important stage because the work to be done now will set the stage for productive fieldwork research in the future. During this stage key actors, who are culturally sensitive and able to be informative to the research will be identified (Fetterman, 2010, pp. 49, 51)**.**

Initially those to be identified include the CEO of the non-government organisation Prisoner Aid and Rehabilitation (PARS); the Health and Disability Deputy Commissioner and the Human Rights Commission senior officer holding the disability portfolio; an ESOL Teacher and Corrections staff and advisors including their Kaumatua Maori Elder, the Director of Prisoner Health and their Policy and Research Adviser.

It will also include identifying the Ministry of Health Disability Support Services senior bureaucrat who will receive the questionnaire to complete. Other key contacts include the University of Auckland Professor with an interest in this area of research (likely to be in Population Health) and the researchers from the University of Auckland Audiology Department.

3.7.5 Fetterman's Ethnographic Adolescent or Adult: Fieldwork (Fetterman, 2010, p. 142)

During the fieldwork stage the researcher will be working with people in their natural settings for a significant amount of time. A considerable amount of work will be done, as the researcher will be playing a very active role of advocate ethnographer to ensure all positive social change recommendations are underscored by evidence and promoting change in public policy to see the required changes initiated.

During the fieldwork stage meetings will be held with the previously identified key contacts, some of who will be formally interviewed. These parties have now been identified and include Mr Barry Matthews, Corrections CEO; Ms Tanya Thomas, Health and Disability Deputy Commissioner; Mrs Karen Newborn Adult Literacy Teacher; Mr Desmond Tihema Ripi, QSO, National Kaumatua Maori Elder at the Department of Correction; Ms Bronwyn Donaldson, Director of Health, Corrections Services, Department of Corrections and Ms Sally Faisander, Strategy, Principal Research Adviser, Policy & Planning, Corrections Services, Department of Corrections; Professor Peter Thorne of the University of Auckland Population Health and Dr. Grant Searchfield and Dr. David Welsh, Audiology Researchers, University of Auckland.

Mrs Karen Newborn, teacher of Adult Literacy will be asked to review the English language content and sentence structure in the Prisoner Questionnaire as many prisoners have lower levels of literacy skills and the language used needs to be easy to read and comprehend. The Questionnaire will be amended according to her recommendations.

In the interview with key contact Mr Desmond Tihema Ripi, National Kaumatua Maori, NZ Department of Corrections, he will be asked to advise if the following research design construct meets with his approval: 50 male prisoners from all ethnicities will self-select to the research with no restriction on whether they are New Zealand citizens or not; the age group will be open and their term of imprisonment needs to be a minimum of three months for reasons of follow up as required.

The research design prisoner participation requirements, as outlined previously will be explained to the CEO of PARS in a face to face meeting and he will be given 75 copies of the Flinders University Prisoner Consent Form and the Prisoner Questionnaire.

In addition, during the fieldwork stage national and international academic and media data will be reviewed with research terms of ear disease, hearing loss/anti-social, criminal behaviours; disability access and equity health care issues, criminality/disability/hearing impairment being applied.

A statistical review of the number of male prisoners currently incarcerated in New Zealand in comparison to international statistics will be done and then the number of New Zealand prisoners with hearing loss as recorded by Corrections will be identified and these findings will be reported in chapter 1.

Then, the New Zealand statistics for the estimated number of people affected by hearing loss will be identified which will then offer the opportunity for the prisoner hearing screening results being the basis of a quantitative objective comparative analysis between the general population and the prison population.

In the literature review various United Nations (UN) Conventions and Charters and New Zealand Acts will be reviewed to determine if an inmate's right to access and achieve equity in health care including hearing testing and hearing loss rehabilitation are enshrined by international rights mechanisms and national legal mandates.

Acts to be reviewed will include the Accident Compensation Act; Corrections Act 2005; Crimes Act 1961; Health and Disability Commissioner Act 1994; New Zealand Bill of

Rights Act 1999 (BORA); Privacy Act 1993; Sentencing Act 2002; The Human Rights Act 1993 and as well the Universal Declaration on Human Rights and the UN Convention on the Rights of Persons with Disabilities will be examined.

3.7.6 Fetterman's Ethnographic Retirement and Last Rites (Fetterman, 2010, p. 149)

When the literature research and review has been completed, the findings narrative will be written up in chapter four as will the questionnaires findings and key contact interviews. Recommendations developed as a result of these findings will be detailed in chapter 5. The thesis will then be submitted and research findings publicly released.

The benefit of using the (Fetterman, 2010, pp. 148-149) life stages ethnographic model is because, as can often happen with research, there may be opportunities presenting that will cause a diversion that leads the ethnographer to consider other areas relative to the purpose of their research. By having it mapped out using the Fetterman life-cycle, the research can be drawn back in-line and on the correct path again.

Also, by applying the ethnographic research design life-cycle, the ethnographer will be able to clearly define when the research is complete and the narrative can be finalized. This may seem obvious but in participatory action research the situation can be evolving over many years, as has occurred with this inquiry and to be able to apply a dispassionate strategic overview by using the ethnographic life-cycle enables certainty of research delivery and eventual closure.

By using Fetterman's life-cycle model it will be easy to identify at which stage of the ethnographic research the flow of the research delivery was disrupted, as occurred during this research.

3.7.7 Ethnographic Life-Cycle Disruption

As an experienced ethnographic researcher the writer believes there is a need to consider the addition of an adjunct, somewhat like a rail way siding, to the Fetterman life-cycle research design model by adding the **Ethnographic Life-cycle Disruption stage**. This stage can occur during any step of the ethnographic research design life-cycle and may force an ethnographer to cease applying the research design and going down a particular research course, thus making the research design partially or even fully obsolete.

In some circumstances it may mean that the research is unable to proceed and premature retirement or implementation of the last rites ethnographic stage would occur. Barriers to

the research design being completed could include key partners retiring; funding being unavailable or even an inappropriate or unworkable research design.

In this ethnographic research **the partial Life-Cycle Disruption** occurred at the Mid-wiving stage when Corrections implemented increasing levels of passive obstruction to the research proceeding. They required amendments to multiple iterations of the Corrections Ethics Committee research application as submitted to the Corrections Strategic Analysis and Research team. It has been labelled passive obstruction because Corrections did not actively state the research could not progress, they just continued to introduce obstructions to it proceeding.

At this point, the elements of Stage one research design that continued to be implemented were the literature review and the key contact interviews. The rail siding that was introduced to accommodate the partial life-cycle disruption, which the writer has called Stage two was a new element of object and subject participatory action research within the mid-wifing stage of Fetterman's ethnographic life-cycle.

3.7.8 Gestation and Birth Stage Revisited

When Corrections proved to be a barrier to the full implementation of the previous, Stage one research design, the impact on the ethnographer was challenging as the need to do this research was high and the response from the government department responsible was quite bewildering and caused confusion along with some frustration. These emotional responses did however drive the determination to ensure the research was done as it showed the level of government antipathy towards the marginalised population of prisoners with hearing loss.

During this time, quite protracted reflection on various research design options showed that there was a path forward and using Fetterman's descriptive ethnographic life cycle, an additional iteration of the Gestation and Birth stage emerged with an opportunity to revisit the research design. Though the initial research design included PARS staff interviewing 50 prisoners when Corrections declined to permit this the writer then developed a research proposal that 50 ex-prisoners would be recruited to the research **after release**.

But practical issues such as recruiting prisoners who had been released and safe interview practices proved insurmountable and it would seem that an impasse had been reached and the research could not progress.

For clarity: in the original research design four questionnaires were to be developed; the first being the Prisoner Questionnaire; the 2nd for PARS staff who interviewed the prisoners completing the Prisoner Questionnaire; the third for Corrections health policy staff to complete and the fourth for Ministry of Health Disability Support Service policy staff to answer.

Following the departure of Corrections and with them PARS, it was evident that only two questionnaires could now be applied in the field as the questionnaires for the prisoners and PARS staff were dropped from the research design.

Though initially this was frustrating and disappointing as it indicated the research design was unable to be implemented, it opened the door for the ethnographer to respond almost immediately to a significant opportunity that became available, which, when it presented, was considered and discussed with the Professors from Flinders University and the University of Auckland.

Though the Flinders University amended ethics partial approval was achieved based on the work being done with Corrections, circumstances evolved whereby Serco Private Prison service in Auckland entered the discussion on the research design and they agreed to the same terms of the research being done, with the number of prisoner participants being increased from 50 to 100. Mr. Steve Hall, Serco Australasia Director of Recidivism Prevention advised he would manage the Serco ethics process required for the research to proceed and he did.

In line with Fetterman's life-cycle analogy, this process could be called the evolution or birthing of the twin design approach, but the weaker twin (Corrections) failed to thrive and fell by the wayside and the stronger twin (Serco Private Prison service) thrived on the challenge of identifying the occurrence of hearing loss in prisoners.

The opportunity that enabled the development of this superior research design was that bought to the table by a new key participant, Serco, a private prison contracting company who offered to include in the research design the hearing screening of 100 self-selected male prisoners (an increase of 50 participants) and with it, a short hearing health questionnaire. This is a genuine occurrence of when one door closes another opens.

However, this ethnographer is not a hearing therapist or audiologist and is unable to implement the hearing screening component of the research questionnaire of 100 self-selected male prisoners. Accordingly, the ethnographer would need to invite a further key

participant to the table who would be able to do as required and discussions began with Life Unlimited, Hearing Services (LUHS).

LUHS is contracted by the New Zealand Ministry of Health to deliver a hearing screening service, which is delivered by trained and qualified hearing therapists. This ethnographer asked LUHS if they would implement the prisoner questionnaire pro-bono and in addition do the hearing screening of 100 prisoners as they have the capacity, using standardized equipment, to do high-tone low-tone hearing tests as requested by Serco. LUHS would ask the prisoners their usual list of hearing health history questions, fortuitously replacing the prisoner current and historical hearing questionnaire intended for implementation by the PARS staff members. Of note, the LUHS questionnaire aims to capture a greater scope of current hearing health information than the original model.

It is during this stage that 100 prisoners on remand at Serco Mount Eden Corrections Facility will answer the hearing health questionnaire and have low tone high tone audiograms done by LUHS hearing therapists.

The questions each prisoner will be asked are their name, date of birth, ethnicity, consent to receiving hearing therapy services and history of any previous hearing assessment. They will also be asked if there is hearing loss in the family, of their noise exposure, if they have any pain, discomfort, fullness or blocked feelings in their ears and whether they have observed a sudden, gradual or fluctuating onset and progression of hearing loss. Also, whether they have tinnitus which is heard in the right ear, left ear or within their head, and if they do have tinnitus whether it is constant or intermittent and the degree of tinnitus annoyance, ranging from zero to ten. The prisoners are also asked if they experience dizziness, imbalance or head injury; whether they have other health issues.

In regards to their hearing capability, prisoners are asked to assess their hearing in the following listening situations: 1 on 1 in quiet, in groups with background noise; on the telephone; when the telephone rings, radio and television and at home, socially or at work.

The results from the LUHS hearing-screening programme testing and questionnaire will be reported in-depth in both narrative and table format, in chapter 4.

3.7.9 Adolescent or Adult Stage Revisited

LUHS agreed to participate in the research and it was planned the prisoner hearing health questionnaire and hearing screening would be implemented one day a week over three

months in 2014 by three qualified hearing therapists who would attend Mount Eden Corrections Facility.

My role as ethnographer, in addition to ensuring smooth merging and implementation of the two ethnographic designs of participatory action research will also include the often hidden tasks of trouble-shooting and relationship negotiations. This will be necessary to ensure the hearing therapists can continue to have safe seamless access to the 100 prisoners. The hearing therapists will be assisting prisoners to voluntarily complete the hearing health questionnaire and have high tone low tone hearing loss screening done and they can give support to the inmates when they answer the basic hearing health questionnaire and ensure the integrity of the testing is not compromised by an unsuitable or unsafe testing environment.

During the second stage fieldwork preparation the ethnographer, Serco Director of Prisoner Health and Serco Director of Recidivism Prevention and the General Manager of LUHS will need to collaborate to establish clear boundaries on matters such as prison access by hearing therapists and the application of New Zealand stringent privacy laws in relation to the identification of the prisoners.

In addition, Serco Mt Eden Corrections Facility staff will need to actively ensure the ethics requirements of this research were met and only recruit prisoners who consented and agreed to sign the participation consent question on the prisoner questionnaire template. Also, practically speaking, a prison officer would need to be available to be with the hearing therapists at all times for safety reasons.

Whether in Geneva, Switzerland, doing Observer work for the International Federation of Hard of Hearing People at the meeting of the United Nations Committee for the Convention on the Rights of Persons with Disabilities for the first month of the screening or elsewhere in the world, the ethnographer will closely track the progress of the prisoners completing the prisoner hearing health questionnaire and hearing screening tests by email to ensure it is done as planned and to rapidly address any concerns

It was agreed by the ethnographer and the General Manager of LUHS that at completion of the hearing screening of 100 prisoners their hearing screening results will be rated according to the following categories: No further action; monitoring; audiological referral; general practitioner referral and referral by a general practitioner to an Otolaryngologist (Ear Nose and Throat surgeon).

The category descriptors are: **No further action**: the prisoner has no indication of hearing loss or ear disease and does not require follow up; **Monitoring**: retest in 12 months as early indications of an emerging issue; **Audiological referral**: the prisoner has hearing loss or indication of some other audiological issue and requires formal audiological assessment; **GP referral**: the prisoner requires clinical care from a General Practitioner and **ORL referral:** the prisoner requires a GP referral to specialist level clinical care.

The 2014 President of the New Zealand Audiological Society, Mr. Mike Severn, will be asked to review these categories to ensure they are appropriate and that all prisoner hearing presentations could be captured in this model. He will also be asked to review each of the prisoner hearing health questionnaires including the low tone high tone audiogram screening test results after they have been categorized to ensure they are allocated correctly.

3.7.10 Retirement and Last Rites Revisited

To recap; because of the need to seamlessly combine the ethnographic life-cycle stage one and stage two research designs there was no retirement or last rights implemented in stage one. When merging the stage one and stage 2 research designs the ethnographer will be responsible for ensuring that the Serco and LUHS hearing screening research collation by category is done accurately and that a senior audiologist offers review and oversight to the research findings to ensure the categorization is clinically correct. The initial categorization was done by the ethnographer, in conjunction with the General Manager of LUHS.

It is also essential to ensure that autoenthnographic advocacy is applied by using the evidence from the prisoner hearing health questionnaire, which will show the historical and current hearing health concerns and low tone high tone audiogram screening results of all participating prisoners. After the results are analysed the hearing rehabilitation needs of the 100 participant prisoners with hearing loss will be unanimously detailed and reported to a range of parties, as outlined in chapter four.

In line with Fetterman's retirement and last rites research design, Serco agreed to ensure the results were given, in a letter, to each prisoner who required immediate hearing intervention. This was agreed, at the first meeting of the ethnographer with Mr. Steve Hall, Serco Director of Prisoner Health and Director of Recidivism Reduction and in a further meeting of all parties with Mrs. Jessica Lissaman, General Manager of LUHS. It was

reassuring to observe the same ethical stance of the prisoner's right to be informed was supported and will be applied by all parties in this research.

To ensure each prisoner is notified of their hearing screening results the ethnographer will assist the LUHS General Manager to develop the four template letters that will be sent to advise each prisoner of their hearing screening results and what type of follow up they need.

Because of the strict New Zealand Privacy Act, the ethnographer and LUHS General Manager will be unable to access the current addresses from the MECF records of prisoners who are completing the prisoner hearing health questionnaire and have high tone low tone hearing screening done. This is of importance because MECF is a remand prison and most of the prisoners would have either been sentenced and relocated to another prison or released by the time the senior audiologist has viewed the raw questionnaire and hearing screening data that has been pre-categorized by the ethnographer and General Manager of LUHS. In addition, the ethnographer and General Manager of LUHS will then be required to develop letter templates to send to prisoners in the four categories that require further follow up which have then to be sent to the Director of MECF for onwards distribution.

When discussing this, and how slow this process will be if it is done correctly, and, as well, for the process to be Privacy Act compliant, the Executive Director of MECF agreed their Health Service would identify where each prisoner is currently located and ensure each prisoner would be sent a letter as provided by LUHS advising of their hearing screening results and the recommended follow up action the prisoner should take.

For those prisoners requiring follow-up, they will be advised by letter to telephone LUHS toll-free 0800 phone number to access the required case management and follow-up.

Before leaving Fetterman's life-cycle research design model and moving on to considering how participatory action research is likely to apply when investigating hearing loss in the New Zealand prison population, advocacy ethnography will now be defined and it's application considered for this research.

Autoenthnographic advocacy (Fetterman, 2010, p. 139) is done when the research is finished and the ethnographer ensures the research results are distributed to the public. Though this action is considered to be a public-relations or political action it is an essential

stage of the research that must done carefully to ensure it achieves the greatest benefit for those whose needs are being highlighted.

It is all well, and good, to do significant research such as this, that could offer important insight to government bureaucrats responsible for the funding and delivery of prisoner health and rehabilitation programmes but if the results are not disseminated in a meaningful way, they will have minimal impact and fail to drive social change.

Therefore, within the confines of Fetterman's retirement and last-rights stage, working as an ethnographic advocate, results will be distributed to the Ministers of Health and Corrections, ensuring they are well informed on the prisoner hearing health questionnaire and hearing screening results and advised about the actions required as supported by the evidence.

Also, the results will be published in appropriate Corrections journals nationally and internationally drawing the issue of prisoners with hearing loss to the attention of Prison Directors globally. As well, it is intended that the participatory actions of the research participants who are working collaboratively to such good effect will be published in appropriate public policy journals.

3.8 Participatory Action Research

Within the structure of Fetterman's ethnographic life-cycle participatory action research will be applied because prisoners, hearing therapists, an ethnographer with lived experience of hearing loss, prison bureaucrats, a senior audiologist and academics from two Universities are all actively collaborating. All of their participation ensures this research enables changes to a priori policy on protecting the rights of prisoners and ensuring a posteriori tests and measures as indicators of better governance in prisons

Accordingly critical analysis of participatory research and disability theory follows, realizing that there are perceived to be "problems with establishing theories about the social world which parallel natural-science theories; and more specifically, for social science in problems with explaining and predicting social activity using abstract, context-independent elements" (Flyvberg, 2001, p. 38).

Flyvberg (2001, pp. 38-39) reported that Socrates believed research theories needed to be abstract, explicit and universal and Descartes and Kant added that they also need to be

discrete and independent of human influences such as institutions and traditions and it must be systematic constituting a whole with factors and properties linked by laws or rules.

Analysis will also be done on whether the policy recommendations from Bowers' (1981) that would address hearing loss induced prisoner marginalisation and loss of social status have been implemented; dialogue and correspondence with the State Corrections service on the need to introduce hearing screening of prisoners; discourse and project design and delivery with the government contracted private prison service Serco and systems advocacy correspondence and meetings with the various Ministers of the Crown responsible for disability and Corrections portfolio's.

For the duration of this research there will be crossing paths of objective and subjective participatory research which will add in elements of complexity and pragmatism that necessitate the use of project management strategies to ensure all parties are well informed and remain committed.

Of note, and as Patton observed (Patton, 2002, pp. 91-96) "most contemporary social scientists who adhere to the scientific method are really post-positivists and are prepared to admit and deal with imperfections in a phenomenologically messy and methodologically imperfect world, but [sic] still believe that objectivity is worth striving for."

In this research, Patton's observation that objectivity is worth striving for (2002, pp. 91-96) is evidenced in the objective audiological hearing screening result reporting, which is a subgroup of data that was collected within the prisoner hearing health questionnaire and could be viewed as a post-positive approach. This is because the prisoner hearing screening results are taken directly from the data observed and a systemic and transparent approach was applied to the interpretation of the data.

Also, all prisoner audiogram results were taken from a machine that has been calibrated to enable standardized reporting though the results were then manually recorded on to the template (see Table 3.8), which is where the opportunity for subjective interpretation is introduced and a more heightened risk of human error could be realised at this point.

The Fetterman research design life-cycle with participatory research and advocacy ethnography is applied and discussed in chapter five, offering the opportunity for further validation of the qualitative, narrative research model.

In closing, is important to recognise that all research is inherently able to be contaminated through researcher bias, whether it be qualitative or quantitative, and the capacity or risk of error occurring sits equally with all types of research.

Please see Table 3.6 that outlines the original Stage one structure of the intended research and Table 3.7 that outlines the Stage two change of research design.

Table 3.6. Ethnographic Research Structure - Fetterman's Life Cycle Model: Stage One

Research Design: Stage One
Pre Natal Care: The Problem and Considerations Research issue identified – 50 prisoners to be interviewed (Corrections) **Gestation and Birth: The Proposal** Ethnographic design developed and participatory action with ethnographic component modeled Questionnaires to be developed and implemented in the Field: Questionnaire One: 50 Prisoners with hearing loss to complete Questionnaire Two: Prisoner Aid and Rehabilitation Prisoner Interviewers Questionnaire Three: Department of Corrections policy staff to complete Questionnaire Four: Ministry of Health Aids and Appliances Policy and contracting staff to complete **Midwiving: External Components** Develop and submit Flinders University Ethics Committee application Develop and submit Corrections Department Ethic Committee application **In Stage one the Ethnographic Life Cycle Disruption occurred at the mid-wiving stage when Corrections stance prohibited progress**

Table 3.7. Ethnographic Research Structure - Fetterman's Life Cycle Model: Stage Two

Research Design: Stage Two
Following the addition of Serco to the research project, Stage two was developed and implemented **Pre Natal Care: The Problem and Considerations** Research issue identified – 100 prisoners to be interviewed (Serco) **Gestation and Birth:** Research proposal revisited and reaffirmed Questionnaires to be developed and implemented in the Field: Questionnaire One: 50 Prisoners with hearing loss to complete Questionnaire Two: Department of Corrections policy staff to complete Questionnaire Three*:* Ministry of Health Aids and Appliances Policy and contracting staff to complete **Midwiving: External Components** Serco Ethics Committee application done **Childhood: Fieldwork Work Preparatory Stage** Research key partners identified and asked to participate **Adolescent/Adult: Fieldwork**

National and International data reviewed
Research relevant information*:* Academic and media reports released nationally and internationally on ear disease, hearing loss/anti-social, criminal behaviours; disability access and equity health care issues; criminality/disability/hearing loss and prisoner health accountability; Human Capabilities Approach; social contract;
New Zealand Acts and United Nations Conventions Reviewed
The ACC Act; Corrections Act 2005; Crimes Act 1961; Health and Disability Act 1994; New Zealand Bill of Rights Act 1999 (BORA); Privacy Act 1993; Sentencing Act 2002; The United Nations Convention on the Rights of Persons with Disabilities (CRPD); Universal Declaration of Human Rights.

Policy Reviews

1. Prisoners access and equity to health care
2. Prisoners access to disability support
3. Policy on criminality and disability and how it relates to and affects people who are hard of hearing.

Retirement and Last Rites: Completion and Closure

Collate Information and Action Systems Advocacy

Analyse and report on the Ministries of Corrections and Health questionnaire results Advocate with Government Ministers of Corrections and Disability Issues about prisoners with hearing loss not being identified in New Zealand prisons Ensure prisoners identified as having hearing loss referred to appropriate follow up
Publish findings.

Table 3.8. Template of Prisoner Hearing Health Questionnaire

HEARING THERAPY SERVICES
PH: 0800 008 011

Date: .../. .../...

Mount Eden Corrections Facility Hearing Screening Project

Name: .....

Name: ..... (First Name) ..... (Surname)

Office use only
NHI No _____
PRN No _____
Therapist _____

Date of Birth: ...../...../ 19 .....

Ethnicity:
☐ NZ European
☐ Asian .....
☐ Maori.....(Iwi).
☐ Pacific Peoples.....
☐ Other .....

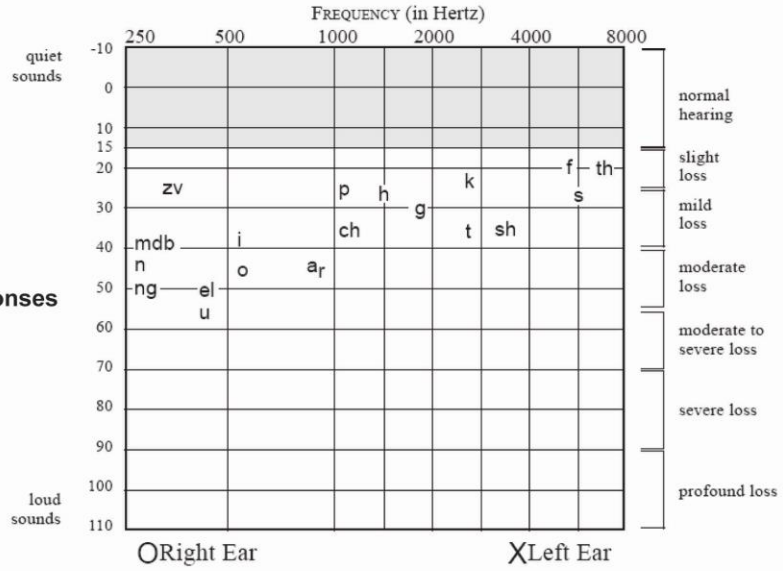
Client Consent

☐ Please tick this box if you **consent** to receiving hearing therapy services.
☐ I know that information I give is collected and securely stored by Life Unlimited Hearing Therapy Services, and that the purpose of the information is to gather data for research. Personal identifiers will not be shared.

Signed: .....

Otoscopy Right Ear_____ Left Ear _____

AUDIOGRAM



Testing Conditions
☐ Sound Treated
☐ Quiet
☐ Elevated Ambient Noise Levels

Reliability of Responses
☐ Consistent
☐ Inconsistent

History:

- Previous hearing assessment: Y☐ N☐
- Hearing loss in the family: Y☐ N☐
- Noise exposure Y☐ N☐
- Pain / discomfort / fullness / blocked feeling in ears: Y☐ N☐
- Onset / Progression of hearing loss: sudden ☐ gradual ☐ fluctuating ☐
- Tinnitus: right ear ☐ left ear ☐ head ☐ constant ☐ intermittent ☐
  annoyance level 0----------→ 10

- Dizziness/ imbalance/ head injury: Y☐ N☐
- Other health issues: _____
  _____
- Difficult hearing situations:
  - •1 on 1 in quiet: Y☐ N☐
  - •in groups / background noise: Y☐ N☐
  - •telephone: Y☐ N☐
  - •telephone ring: Y☐ N☐
  - •radio and TV Y☐ N☐
  - •home / social / work Y☐ N☐

CHAPTER FOUR

DEFINING THE REALITY

4.1 Research Reporting Structure

In chapter one the marginalisation of prisoners with hearing loss was identified as the issue for research. Then, the research aim and design were outlined and the New Zealand prison environment and the policy maker's probable response to this thesis were defined

Then, in chapter two the Human Capabilities Approach was examined and consideration was given to how it applied to both children and prisoners with hearing loss. In addition, the theory of social contract was analysed from the perspective of whether the State had a duty to provide disability accommodation and rehabilitation for people who are unable to be equal contractual partners to it, including prisoners with hearing loss. Consideration was then given as to whether this could be done through the social contract or whether the Human Capabilities Approach applied through the Convention on the Rights of People with Disabilities was the bridge that would enable the application of the State's duty. Following this was a review of relevant Acts and UN Conventions and how they can be applied to ensure prisoners with hearing loss are able to access audiological health care.

Multi-method qualitative research including ethnography, auto-ethnography, subjective and objective participatory action research and critical systems thinking were analysed in chapter three. As this is a complex issue multi-partners participatory action research incorporating Fetterman's life-stages ethnographic framework was required to ensure it was sufficiently investigated.

In this chapter, the structure for reporting the research findings will be sequential with the statistical literature review results being reported first; then the prisoner questionnaire findings with their hearing screening results, followed by the Corrections and Ministry of Health policy questionnaire results. Policy comment will then follow, analysis of which will be done in chapter five.

4.2 Statistical Literature Review Findings

4.2.1 General Population Hearing Loss Statistics

It is important to recognise there are significant variations on hearing loss statistics globally and though the World Health Organisation reports that 360 million people globally or 5.4% of the worlds' population have hearing loss which causes significant disability (World Health Organization, 2015) this statistic is regularly challenged.

Both the Action on Hearing Loss (2010) United Kingdom, and the Deafness Forum of Australia, state that at least 1:6 or 16.7% of the general population have some type of hearing loss. Action on Hearing Loss also reports there are approximately 900,000 people with severe to profound hearing loss, from a general population of 64.1 million in the United Kingdom, equating to 1.4% of the general population having severe to profound hearing loss.

By applying the 1:6 or 16.7% occurrence rate to the New Zealand general population of 4.5 million, over 700,000 New Zealanders have some type of hearing loss, ranging from mild to profound. When applying 1.4% to the New Zealand general population statistics of 4.5 million, approximately 63,000 New Zealanders have severe to profound hearing loss.

The Minister for Broadcasting quoted the New Zealand Census statistics at the Captioning Awards ceremony held on November 25, 2015, that 1:9 or 11.11% New Zealanders have hearing loss, but this rate is not in accordance with statistics as reported by reputable organisations in the United Kingdom and Australia. Accordingly, for the purpose of this thesis, approximately 700,000 New Zealanders have some type of hearing loss, of which approximately 63,000 have severe to profound loss.

Deaf Aotearoa New Zealand CEO Lachlan Keating verbally advised the writer that 11,000 people use New Zealand sign language as a primary form of communication indicating that approximately 52,000 people with severe to profound hearing loss use other forms of communication support such as cochlear implants and hearing aids with or without remote microphones.

4.2.2 New Zealand Prison Population Hearing Loss Statistics

It is reported in the New Zealand Prisoners Health Survey (2005) that prisoners self-report a hearing loss incidence of 1:3. These findings are slightly lower than US research on prison populations where hearing loss occurrence is reported as 36% to 48%. But the

difference can be attributed to the fact that New Zealand prisoners are verbally self-reporting rather than actually being hearing screened.

Of the 1:3 prisoners self-reporting hearing loss in New Zealand, 14.2% of prisoners reported experiencing difficulty hearing someone in a quiet room; 24% experienced difficulty hearing someone on the other side of a room and 31.2% experienced difficulty when having a group conversation.

Prisoners also reported in the New Zealand Prisoners Health Survey (2005) that their access to medical care is haphazard. In a study done in British Columbia (Dahl, 2002, p. 3) it was reported that Canadian Corrections staff were five times more likely to perceive behaviours relating to inmate behavioural or personality problems as deviant rather than a person attempting to overcome communication challenges in a volatile and unstable environment. In the same research 55% of the inmates with partial hearing loss expressed concern about being misjudged, or mislabeled.

It is evident from the Bowers Report (1981) and the New Zealand Prisoners Health Survey (2005) that there is a high rate of hearing loss in the New Zealand prison population. In fact, hearing loss was the most frequently advised sensory disability self-reported by New Zealand prisoners in 2005.

Accordingly, Stanley's statement that it "… is evident there is a need for further data on, and specific monitoring of provisions for diverse groups [in prisons]…particularly prisoners who have physical or intellectual disabilities" (Stanley, 2011, p. 7) has merit and further research is required.

As reported in chapter one, Table 1.2, indigenous Maori and Pacific People are over-represented in prison populations whereas Asian and Europeans ethnicities are under-represented. This information is vital for policy developers who will need to place a strong emphasis on including appropriate cultural designs in all programs aimed at preventing marginalisation and reducing recidivism. To do otherwise is likely to lead to low rates of program uptake and negligible impact on recidivism rates.

Following this discovery, in 2011 Mr. John Harwood (Chairperson, National Hearing Association) and the ethnographer met with Corrections senior staff and research participatory key contacts Donaldson and Faisander to discover the degree of prisoner hearing loss screening being done by Corrections.

Donaldson and Faisander both confirmed there was no hearing screening being done to identify hearing loss in prisoners at Corrections facilities, which unequivocally confirms that Bowers' policy recommendations for hearing screening of prisoners in New Zealand Prisons have not been implemented.

In closing the statistics reporting section, evidentially there is a lack of agreement on the occurrence rates of hearing loss globally.

It is also evident there is a lack of specific hearing loss recognition in prisoners, which is contrary to Bowers' 1981 policy recommendations and has enabled the continuance of marginalisation of prisoners with hearing loss in New Zealand prisons for a further 30 years which is unconscionable.

4.3 Research Questionnaire Responses

In the adolescent and adult stage of the ethnographic life-cycle where the field work was done, information from 100 Prisoners on remand at Mount Eden Corrections Facility (MECF), the Department of Corrections (Corrections) and Ministry of Health was sourced through three questionnaires.

The process of applying each questionnaire in the field will now be examined including the barriers to information sourcing, commencing with the Stage One Prisoner Questionnaire, followed by the Stage Two Prisoner Questionnaire and then by the respective responses to the Ministry of Health and Corrections Questionnaires.

After developing the Stage One Prisoner Questionnaire there were considerable barriers to it being implemented. The following discourse outlines a three-year period, showing the trials and tribulations the ethnographer endured and the alternative pathways and strategies used to overcome the blocks to progress.

4.3.1 Stage One Prisoner Questionnaire

It is important to recognise that the writer dedicated an extensive amount of time to developing the first prisoner questionnaire for 50 prisoners to complete, which was not implemented because Corrections declined to participate, despite it being designed as Corrections wanted. It was designed with questions that were quite limiting and by the tone of the questionnaire, closed answers were sought. The first questionnaire was divided into three sections. Section's two and three were to be completed by the prisoner if

their section one answer rated a score of 3 or above, indicating a need for further hearing loss investigations.

Section one of the first questionnaire was designed to identify if, in fact, there was cause for concern about the individual prisoner's state of hearing; section two aimed to discover the prisoner's educational history and section three sought demographic information including duration of incarceration and Iwi or tribal affiliations.

Combined, the information sought would be able to identify hearing loss indicators; educational attainment and rehabilitative support provided, thereby determining if policy was in place to prevent hearing loss induced marginalisation as previously identified by Bowers.

Two iterations of the Stage One Prisoner Questionnaire were provided to meet the Flinders Social and Behavioural Research Ethics Committee requirements, who gave provisional permission for the research to proceed with the contingency being that the Corrections Ethics Committee also had to give consent for it to proceed too.

However, numerous further iterations of the Stage One Prisoner Questionnaire were required and developed in response to Corrections requirements, as sought by Sally Faisander, Strategy, Principal Research Adviser, Policy & Planning Department of Corrections. In total, there were 47 emails between Faisander and the writer, where she requested a continuous stream of changes to the Stage One Prisoner Questionnaire template and as each requirement was met so another request was forthcoming.

The Corrections Ethics Committee application, in which the Stage One Prisoner Questionnaire template and the Questionnaire templates for Corrections and the Ministry of Health were included, was submitted to Faisander at Corrections on 15 May, 2011; 20 July, 2011; 26 October 2011 and finally on May 10, 2012.

Some of Corrections requirements were, in and of themselves not unreasonable but they were non-essential, time consuming, delayed the research process and the need for some could, legitimately, be challenged. However, the power imbalance was evident during this dialogue as Corrections was able to continue requesting changes that, as an independent ethnographer, there was limited scope for this writer to contest.

One positive outcome of Faisander's requirements is that the ethnographer was required to gain Kaumatua (Maori elder) support for the research. In discussion with mentor

Professor Thorne, from the University of Auckland, he recommended that Faisander be asked to link the ethnographer to the Department of Corrections Kaumatua. This was achieved by Faisander, somewhat reluctantly, who introduced Desmond Tihema Ripi, QSM, Corrections National Maori Kaumatua by email. As ethnographer the writer contacted Desmond by email and established research credentials and then sent a meeting invitation which he accepted.

On meeting with Desmond it was heartening to hear he believed the Prisoner Questionnaire was well overdue, should be answered by randomly selected prisoners of all ethnicities and that he had tried to get the same research done in the late 90's, without success. He was very pleased to see the research being done and offered unfettered support to it proceeding. He also reviewed the questions being asked in the Stage One Prisoner Questionnaire and advised all were suitable.

[redacted] This paragraph has been removed due to confidentiality.

Working positively and from the approach that the research would occur, the following documents were developed and approved by the Flinders Ethics committee: Pro-forma Letter of Introduction to Ex-Prisoners; Pro-forma Letter of Introduction to Other Groups (which was used when the ethnographer met with Prisoners Aid and Rehabilitation Society); Consent Form for Participation in Research (by questionnaire) and Invitation to Participation.

Though all of the materials for the research were prepared and authorized for use there were still many barriers to the research proceeding. This was a trying time as so many doors refused to open and the general attitude prevailing across the hard of hearing health professional sector was cynically negative because many had tried previously to gain Corrections' consent to develop prison population hearing loss diagnostic and therapeutic program's without success.

The most significant barrier was Corrections steadfast refusal to allow a hearing loss detection research pilot to proceed. Even though, the writer would have made every effort to ensure it would not have been a cost burden to Corrections, they persisted in blocking the research.

A steady stream of barriers to progress would be sufficient to stop most researchers, as they would recognise the sheer futility of continuing to strive to meet Corrections impossible requirements. [redacted] This paragraph has been removed due to confidentiality.

Though given provisional consent from the Flinders University Social and Behavioural Research Ethics Committee and significant support for implementation by Corrections Kaumatua (Maori Elder), the Stage One Prisoner Questionnaire was not applied in the field as Corrections persisted in presenting as a significant barrier.

From living with the challenge of having a disability and knowing how its impact weaves across and through every thread of the writer's life, the notion of giving up on defining this wicked problem and failing to assist prisoners who are hard of hearing to achieve their life capabilities was simply not an option.

Most things are possible with good will and a positive approach and following reflection, other strategies were considered and discussed with Associate Professor Janet McIntyre (Flinders University) and Professor Peter Thorne (University of Auckland).

Professor Thorne suggested the writer meet with Dr. Grant Searchfield, Audiological Service Director, and researcher Dr. David Welch, both from the University of Auckland, to discuss their views on the best way forward, which occurred. From that meeting came the suggestion by Dr. Searchfield that the question as asked in the New Zealand Census on hearing loss be included in the Corrections Prisoner Health Survey (also known as the MOI), generally completed with each prisoner on day 7 of incarceration. The writer considered this suggestion had merit, and identified the question, as defined in Table 4.1.

This option was discussed in depth with Professor Janet McIntyre (Flinders University) and it was agreed that it was probably the most productive path forward at this time as no progress was being made in any other direction.

Table 4.1. 2001/2002 New Zealand Census Survey Hearing Loss Questions

Categories of Hearing Disability
Can hear conversation with three other people but with difficulty

Cannot hear conversation with three other people
Can hear conversation with one other person but with difficulty
Cannot hear conversation with one other person

The ethnographer approached Donaldson, Health Director at Corrections to recommend they include the hearing loss screening question in the New Zealand Census Survey to which she agreed and advised it would be trialed at Springhill Prison in the Waikato region, which was very pleasing. Though there was no indication or agreement that Corrections would act on the information given by prisoners, at least it was a step forward in that by asking this question they may begin to realize they had a wicked problem, which they would then be obliged to begin to address.

The ethnographer and Donaldson met again on 6 June 2013 to follow the progress of the prisoners being asked the question outlined in Table 4.1 and Donaldson reported as follows:

> Springhill Prison, Waikato had decided to go further than asking the question, instead they had been hearing testing, by doing high tone; low tone hearing tests with head phones. As a result of this screening from March to June 2013, 19 prisoners have required ear syringing to clear wax build-ups but no other type of hearing loss was identified.

Donaldson's advice was astounding as the ethnographer genuinely believed a collaborative partnership had been established with both parties working together to identify the rate of response to the agreed questions.

But, instead, and unbeknown to the ethnographer, Corrections and Bay Audiology, a national for-profit company, trained two Corrections Nursing staff members on how to use simple non audiogram hearing screening equipment. Of 130 prisoners, 19 were identified as requiring wax cleaned out and no other type of hearing loss was identified.

As ethnographer, this information was received by the writer with a high degree of skepticism bordering on disbelief and Donaldson was quizzed why Springhill Prison test results should be so divergent from other national and international findings on the rate of hearing loss in prisoners.

She said she thought the underlying problem was that the nurses were Corrections employees and the prisoners did not trust them, therefore they would not answer the screening questions accurately.

Then, Donaldson further advised that the management at Springhill had decided to do hearing screening of all 950 inmates using the same process they had already applied. Donaldson was strongly urged by the writer to not go down that path and instead to use independent and properly trained hearing screening therapists or audiologists using standardized audiogram equipment.

The ethnographer then contacted Mr. James Whittaker, Managing Director, Amplifon New Zealand, the parent company of Bay Audiology, to discuss the administration of hearing tests by nursing staff unskilled in matters audiological at Springhill Prison. During our discussion it was determined that he would write to Donaldson at Corrections offering to do appropriate testing of prisoners. This offer was not accepted by Corrections as the service from Bay Audiology would not be cost-free.

At first glance it appears the hearing screening results were spurious as the prisoners did not trust the testers and the testers, who are not trained hearing therapists or audiologists, may also be doing the tests poorly or interpreting the results inaccurately. There has also been anecdotal reporting from audiologists that the equipment provided by Bay Audiology to Corrections was unreliable and should not have been used for this purpose.

Until these issues were addressed, it was inappropriate to expand the testing to the full 950 prisoners at Springhill Prison as Donaldson advised they were about to implement. At this point it was made very clear to Donaldson that as ethnographer the writer could not support the path they were following.

The results of Corrections hearing screening at Springhill Prison highlights what happens when a service does not apply ethical practices, exposing at-risk prisoners to what they perceive as an unsafe environment in which they are unable to honestly disclose sensitive or personal information that could make them appear to be more vulnerable and of a lower social status.

The Corrections hearing screening results at Springhill Prison do not align with any reported nationally or internationally and with their suggested approach, Corrections has left themselves open to an allegation of negligent practices. Of note, a short time after this discussion with Donaldson, prison riots erupted at Springhill Prison. This underscores Donaldson’s remark regarding trust between the staff and inmates, which indicates there was a negative culture prevalent at Springhill Prison at that time (stuff.co.nz, 2014).

In August 2014 the writer was most concerned to learn further that the Corrections Youth Justice system is now using the hand held hearing screening tool as used at Springhill which is a travesty. If appropriate hearing tests were done with this group of at-risk youth their life paths could be considerably, positively, altered.

In conclusion to the implementation of Stage One Questionnaire One, it became apparent that all hope of interviewing Prisoner's in a Corrections facility was rapidly disappearing and that the ethnographic multi-partner participatory research design was unable to be implemented, until a fortuitous opportunity then serendipitously presented.

4.3.2 Stage Two Prisoner Questionnaire

As previously outlined in chapter two, in 2014 when The National Foundation for the Deaf advertised through the New Zealand Institute of Directors for more Board members, co-incidentally Mr. Steve Hall, Director of Recidivism Prevention for Serco Australasia responded to the advertisement and an opportunity presented to discuss the issue of hearing loss in prisoners and the New Zealand research findings to date. These discussions then led to the participatory action research component of Stage One being redesigned and labeled Stage Two.

Stage Two of the research design included 100 self-selected male prisoners having their hearing screened by fully trained hearing therapists which co-incidentally is the same number of prisoners that Bowers tested. The hearing screeners were employed by Life Unlimited Hearing Services, which is a non-government, registered charity who are funded by the Ministry of Health to provide hearing rehabilitation services. Of note, they use standardized equipment to do high tone low tone audiograms.

The documentation and process for the ethics application to the Serco Ethics Committee was managed by Mr. Steve Hall of Serco. The format of the Stage Two Prisoner Questionnaire template as proposed by Life Unlimited Hearing Services was reviewed, edited and accepted by Serco and the ethnographer as it complied with the New Zealand Privacy Act and the Health and Disability Code of Rights and would elicit information on hearing health, individual and family hearing histories and current health status from each prisoner in the project.

The key difference between the Stage One Prisoner Questionnaire and the Stage Two Prisoner Questionnaire is the absence of questions on the prisoner's educational history. However, in the latter, an audiogram hearing screening test has been included, thus it was

more informative about the prisoner's current hearing health status than the Stage One Prisoner Questionnaire would have been.

The hearing therapists visited Mount Eden Correction Facility between May and July 2014. The prisoner hearing screening component was managed by both Jessica Lissaman, General Manager, Life Unlimited Hearing Services and as ethnographer the writer managed the relationship and communications with Serco Directors and ensured on-going safe access to the Mount Eden Corrections Facility for the hearing therapists. This was a functional and effective model for doing such a project, as all parties including the Serco Directors were engaged and supportive which was vastly different to the earlier response received from Corrections.

The ethnographer was also relieved that the persistence, research and advocacy work that had been done previously would now bear fruit and be applied to this thesis.

4.3.3 Schedule of Prisoner Hearing Health Questionnaire Responses

100 self-selected prisoners were hearing screened with high tone low tone hearing tests and asked a series of hearing health questions. Their responses to the questions were recorded by the hearing therapist who wrote them down on a standardized template which was used by all prisoner respondents. The results of the 100 prisoners responding to the questionnaire are detailed as per the categories of result No further action; monitoring; audiological referral; General Practitioner referral and referral by a General Practitioner to an Otolaryngologist (Ear Nose and Throat surgeon) as set out in Tables 4.2 to 4.7.

Table 4.2. Category: No Further Action

In this category twenty-four prisoners have very minor to no indication of hearing loss or ear disease and does not require follow up.

Number	Ethnicity	Category: No further action
1	Maori	Normal hearing Previously tested No Tinnitus No hearing loss noticed Type 2 Diabetic Has had industrial noise exposure

Number	Ethnicity	Category: No further action
2	Maori	Slight loss right ear Normal hearing left ear Intermittent Tinnitus No hearing loss noticed Asthma Has had industrial noise exposure
3	Maori	Slight loss both ears Tinnitus in left ear Dizziness/Imbalance most of the time No hearing loss noticed but hard to hear on phone Possibly has heart issue Has had industrial noise exposure
4	Maori	Has slight hearing loss both ears Gradual progression of hearing loss Right ear pain Dizziness/Imbalance after aural toilet Difficult to hear in background noise Broken foot
5	Maori	Has normal hearing Has had industrial noise exposure Painful ears when blocked Head injured and in coma for 6 days last year
6	Maori	Has slight hearing loss both ears Dizziness/Imbalance daily for a few seconds
7	Maori	Has normal hearing Previous hearing test done Family history shows his sister has hearing loss Has had industrial noise exposure Ear ache right ear Tinnitus which is intermittent right ear Difficult to hear in background noise
8	Maori	Has slight hearing loss both ears Industrial noise exposure Tinnitus which is intermittent both ears Asthma
9	Maori	Has slight hearing loss both ears Industrial noise exposure
10	Other	Has slight hearing loss both ears Industrial noise exposure Tinnitus which is intermittent in left ear Blocked feeling in ears

Number	Ethnicity	Category: No further action
11	Pacific Peoples Fijian/Indian	Has slight hearing loss both ears Industrial noise exposure
12	Pacific Peoples	Has slight loss right ear Normal hearing left ear Industrial noise exposure
13	Asian	Has slight loss both ears No other history
14	European	Has slight hearing loss right ear Normal hearing left ear Industrial noise exposure Previous hearing assessment Head injury with concussion and burns Excema Has difficulty hearing in groups and on the telephone
15	European	Has slight hearing loss right ear Normal hearing left ear Intermittent Tinnitus in left ear Industrial noise exposure
16	European	Has slight hearing loss right ear Normal hearing left ear Intermittent Tinnitus Noise exposure from music Rheumatoid Arthritis Head injury Previous hearing test done
17	European	Has borderline slight hearing loss both ears Family history; paternal grandparents have hearing loss Industrial noise exposure over 4 years with intermittent use of hearing protectors Pain in ears; ears block in the shower History of head injury and multiple concussions Does not like loud noises Difficult to hear on the telephone
18	European	Has borderline slight hearing loss both ears No other history
19	European	Has slight hearing loss both ears Head injury in car crash 2012

Number	Ethnicity	Category: No further action
20	European	Has slight hearing loss right ear Normal hearing left ear Head injuries aged 5 and again in teens Maternal grandfather has hearing loss Possible noise exposure
21	European	Has mild hearing loss right ear Slight loss left ear Previous hearing assessment done Nil perceived hearing loss
22	European	Has slight hearing loss right ear Normal hearing left ear Previous hearing test done Tinnitus High level of industrial noise exposure Dizziness/Imbalance (attributed by prisoner to coffee) Difficult to hear in background noise and in groups
23	European	Has slight conductive and high frequency hearing loss Family history Noise exposure No reported difficulties
24	European	Has slight high frequency hearing loss Some noise exposure

Table 4.3. Category: Monitor Again in 12 Months

In this category it will be recommended to twenty-six prisoners that that they seek a hearing re-screen in 12 months as there are early indications of an emerging issue

Number	Ethnicity	Category: Monitor again in 12 months
25	Maori	Some self-reported difficulties of hearing; Head injured; had noise exposure; has Tinnitus Has some discomfort in ears and history of previous assessment Slight hearing loss in high frequency Asthma
26	Maori	Has slight hearing loss in high frequency Previous history Noise exposure Feeling of fullness in ears at time Head Injury
27	Maori	Has mild hearing loss in high frequency

Number	Ethnicity	Category: Monitor again in 12 months
		Previous assessment done Family history of hearing loss Noise exposure Occasional feeling of discomfort Some self-reported difficulty with hearing
28	Maori	Hearing appears normal Previous history Noise exposure Left ear only has some pain and has Tinnitus in both ears Some self-reported hearing difficulty
29	Maori	Has slight to mild across the board hearing loss Little bit of noise exposure Minor blocked ears
30	Maori	Has mild conductive hearing loss Noise exposure Some Tinnitus Asthma
31	Maori	Has slight to mild high frequency loss Some noise exposure
32	Asian	Has mild high frequency loss Some noise exposure Mild Tinnitus
33	European	Has mild to moderate high frequency loss Had hearing assessment done during childhood Some noise exposure Minor difficulties hearing
34	European	Has slight mid to high frequency hearing loss Previous assessment Noise exposure
35	European	Has mild conductive and slight high frequency loss Previous assessment Some hearing loss in family Some Tinnitus History of infections Reports as hearing well
36	European	Has slight to mild high frequency loss Does not report difficulty hearing Diabetic
37	European	Has slight to mild high frequency loss
38	European	Has mild conductive and slight high frequency loss

Number	Ethnicity	Category: Monitor again in 12 months
		Had previous assessment Has elevated blood pressure and dizziness No reported hearing difficulties
39	European	Has mild hearing loss Head injury as a child Noise exposure Tinnitus Gout
40	European	Has mild Hearing Loss Head Injury Had previous assessment Hearing loss in family Noise Exposure Some hearing difficulty
41	Pacific Peoples Samoan	Has slight loss hearing left ear Moderate loss right ear Hearing loss in family Noise exposure Some Tinnitus
42	European	Has mild hearing loss left ear Difficulty hearing radio and TV Ears get blocked with wax
43	Pacific Peoples Niue	Has slight hearing loss Previous hearing assessment Noise exposure Ears blocked Tinnitus both ears
44	Pacific Peoples Samoan	Has slight loss both ears Had previous hearing assessment done Industrial noise exposure Has Tinnitus which can be pulsatile on exertion Sometimes “sees stars” Has history of head injury/imbalance/dizzy
45	Pacific Peoples Tongan	Has slight loss both ears Industrial noise exposure Tinnitus both ears Dizziness sometimes Difficulty hearing radio and TV
46	Pacific Peoples Tongan	Has slight loss right ear Mild loss left ear Previous hearing assessment Industrial noise exposure Finds loud sounds annoying

Number	Ethnicity	Category: Monitor again in 12 months
		Gets ringing in ears when putting on headphones Head injured Talks loud on telephone Has difficulty hearing in groups and with background noise
47	Pacific Peoples Fijian/Indian	Has slight hearing loss left ear, mild hearing loss right ear Family history hearing loss Industrial noise exposure Intermittent Tinnitus both ears
48	Pacific Peoples Samoan	Has mild hearing loss both ears Previous hearing assessment
49	European	Has mild to moderate loss left ear Moderate to severe loss right ear Says results are similar to those recorded 3 or 4 years ago in South Auckland Asthma
50	Maori	Has moderate loss right ear Borderline moderate to severe loss left ear Previous hearing assessment done No hearing loss in family Industrial noise exposure No issues with hearing loss reported

Table 4.4. Category: Audiological Referrals

It will be recommended to thirty-one prisoners that they have a formal audiological assessment by an Audiologist as there are indications of a significant issue with their hearing.

Number	Ethnicity	Category: Audiological Referrals
51	Maori	Has slight to mild mid frequency hearing loss No history or previous assessment Has head injury Reports some difficulties and possibly Auditory Processing Disorder
52	Maori	Has slight to mild across the board hearing loss Previous assessment, some noise exposure Some Tinnitus Head Injury with possible Auditory Processing Disorder Asthma, Diabetic

Number	Ethnicity	Category: Audiological Referrals
53	Maori	Has slight to mild across the board hearing loss Family History Noise exposure Some Tinnitus Some difficulty hearing
54	Other Eastern European	Has slight high frequency hearing loss Previous assessment Some noise exposure Intermittent high pitched Tinnitus Head Injury and has some difficulty hearing which may indicate he has Auditory Processing Disorder
55	Pacific Peoples Cook Island	Has moderate loss both ears Hearing loss in the family as his father wears hearing aids No previous hearing assessment done Tinnitus both ears Industrial noise exposure Gradual hearing loss onset Difficult to hear with background noise and over distance Has Diabetes Type 2
56	Pacific Peoples Tongan	Has mild loss right ear Moderate loss left ear Industrial and music noise exposure Some Tinnitus History of short episode of dizziness/imbalance/head injury 2 years ago No previous hearing assessment done
57	Maori	Has mild to moderate loss in both ears Previous hearing assessment done Head Injury Has difficulty hearing in groups and background noise and sometimes on the telephone; radio and television and in social settings
58	Pacific Peoples	Has slight hearing loss right ear Pressure in ears and behind eyes – needs to Valsalva Head Injury Tinnitus both ears Industrial Noise Exposure Wears glasses

Number	Ethnicity	Category: Audiological Referrals
59	European	Has borderline moderate to severe hearing loss both ears Industrial noise exposure Had cold/sinus infection and recent balance/dizziness issue Finds it difficult to hear in background noise and on the telephone and is more sensitive to noise
60	European	Has mild loss right ear Severe loss left ear Had previous assessment done Industrial noise exposure Fullness and blocked ears sometimes Difficulty hearing in groups and background noise and socially Burst TMR; broken nose set off migraines 20 years ago Diabetic
61	European	Has moderate to severe loss left ear Severe loss right ear Had grommets as a child Previous hearing assessment done Industrial noise exposure Head injury
62	European	Has slight loss right ear Mild to moderate loss left ear Industrial noise exposure for 10 years No previous hearing assessment
63	European	Has moderate loss both ears Previous hearing assessment Industrial noise exposure Blocked ears and ear infections Gradual progression of hearing loss High Cholesterol and hardened arteries to heart Difficult hearing radio and television
64	European	Has moderate hearing loss both ears Head Injury Diabetic Industrial noise exposure for 26 years Previous hearing assessment Gradual onset of hearing loss Difficult to hear in all situations except one to one and when the phone rings

Number	Ethnicity	Category: Audiological Referrals
65	European	Has borderline moderate loss both ears Previous hearing assessment done Industrial noise exposure Head injury in car crash about 7 years ago Difficult to hear radio and TV
66	European	Has moderate loss both ears Industrial noise exposure 13 years Dad has older onset hearing loss Head injured twice
67	European	Has moderate loss left ear Mild loss right ear Previous hearing assessment done Industrial noise exposure Had grommets placed in both ears to treat infections Has Tinnitus in both ears Finds it difficult to hear in 1 on 1 quiet; in groups/background noise; on telephone; watching television; hearing radio and television
68	European	Has mild loss both ears No previous hearing assessment Industrial noise exposure for16.5 years Head injured when aged 12 years Asthma
69	European	Has slight loss both ears No previous hearing assessment Father has age loss Industrial noise exposure Right ear aches and loses hearing in it sometimes Has dizziness and imbalance and can black out sometimes when he stands up History of head injury and been involved in many fights and car accidents Has heart murmurs and palpitations Asthma Has difficulty hearing in groups and in background noise and hearing TV and radio and in social settings.
70	European	Has moderate to severe loss both ears No previous hearing assessment Father has age loss Industrial noise exposure Tinnitus right ear Difficult hearing in groups and in background noise and on the telephone and hearing radio and television and hearing from a distance

Number	Ethnicity	Category: Audiological Referrals
71	Asian	Has moderate loss left ear Moderate to severe loss right ear Previous hearing test done in Remuera in the 1980's showed good hearing A bit more difficult to hear in groups and with background noise
72	Asian	Has severe loss left ear Moderate loss right ear No previous hearing assessment done Right ear uncomfortable Telephones are hard to hear
73	Maori	Has severe loss both ears No previous hearing assessment Daughter has hearing loss Industrial noise exposure 19 years Throbbing inside ears Tinnitus in both ears Head injury in 1980's Difficult to hear in groups and with background noise Telephone volume has been adjusted Finds it difficult to hear at home socially and at work Cannot distinguish what is said
74	Maori	Has moderate hearing loss left ear Mild hearing loss right ear Previous hearing assessment done No hearing loss in family Industrial noise exposure 5 years Sometimes ears uncomfortable No Tinnitus Some dizziness/imbalance/head injury Has Hepatitis B and Hepatitis C Depends on the level of background noise whether he can hear radio and television
75	Maori	Had severe loss right ear Borderline moderate to severe loss left ear No previous hearing assessment Family history hearing loss – Mum, Uncle and nieces Noise exposure – loud music Tinnitus left ear mostly Difficulty hearing in groups and in background noise and it depends on the speaker

Number	Ethnicity	Category: Audiological Referrals
76	Maori	Had moderate to severe loss right ear Mild loss left ear Right eardrum perforated Previous hearing assessment done Industrial noise exposure Intermittent Tinnitus occurs in his right ear Difficult hearing situations: In groups/background noise Telephone needs to be turned up Telephone ringing Radio and television
77	Maori	Had moderate loss right ear Borderline moderate to severe loss in left ear Previous hearing assessment done No hearing loss in family Industrial noise exposure No issues with hearing reported
78	Maori	Had borderline moderate loss left ear Moderate loss right ear Previous hearing assessment done No hearing loss in family Wore headphones in noisy workplace Tinnitus both ears Head Injury with concussions Experiences difficulty hearing in all categories and sometimes with hearing the telephone ringing and radio and television
79	Maori	Had mild loss right ear Borderline moderate loss left ear Previous hearing assessment done No hearing loss in family Industrial noise exposure Has ear ache Left ear wax build up Tinnitus both ears Hearing dull Stroke 2 years ago Diabetic Had Bells Palsy 3 years ago Has difficulty hearing in group or with background noise; radio and television hard to hear

Number	Ethnicity	Category: Audiological Referrals
80	Maori	Right ear hearing normal; Left ear has borderline moderate loss; had previous assessment done No history of hearing loss in family Industrial noise exposure 5 years Pain in right ear; Tinnitus in right ear Dizziness/Imbalance/Head injury: Yes No issues with hearing reported
81	European	Has borderline mild to moderate loss both ears No previous hearing assessment Father wears hearing aids Industrial noise exposure Onset gradual; Tinnitus both ears White noise at night 6/10 irritation Difficulty hearing in a group and on the telephone

The prisoner questionnaire responses and prisoner audiogram results highlight a posteriori there are emerging areas of concern. These reflect there is a need for Serco in their governance role to be proactive in their response by introducing in their governance practices hearing screening policy. This would introduce hearing preservation as a preventative measure in the prisoner well-being programme thus enhancing prisoner human capabilities. It is also vital that both Corrections and Serco ensure their prisoner programmes for health, well-being and recidivism prevention are capabilities based, showing what a prisoner can and is able to do rather than only being driven by fund holding and social harm prevention.

Table 4.5. Category: General Practitioner Referral

In this category four prisoners require follow-up clinical care from a General Practitioner

Number	Ethnicity	Category: GP Referral
82	Pacific Peoples Samoan	Moderate loss left ear and slight loss right ear No history of hearing loss in the family Industrial noise exposure Sometimes ears feel uncomfortable Tinnitus in right ear constant, in left ear sometimes No issues with hearing reported and no previous test

Number	Ethnicity	Category: GP Referral
83	Pacific Peoples Tongan	Asymmetric hearing loss for ORL referral Previous hearing assessment Industrial noise exposure 2 years Has intermittent Tinnitus in both ears Head injury caused when fell backwards on concrete Reports difficulty in hearing in groups and with background noise, radio and television are both
84	Pacific Peoples Cook Island	Moderate loss both ears Previous hearing assessment Had grommets Brother and cousins have hearing loss Industrial noise exposure – used ear plugs Uses nasal spray Noticed hearing loss in teens Asthma Hard to hear in background noise and in groups Uses left ear for telephone Radio and television volumes louder than usual Hard to hear socially/home/work sometimes
85	European	Borderline moderate loss left ear and moderate loss right ear but no previous hearing assessment No history of hearing loss in the family Industrial noise exposure 4 years Intermittent Tinnitus left ear causes headache Head injury left side at 16 years of age when fell out of car; Dizziness and nausea for 6 weeks Has high blood pressure and reports difficulty in hearing in groups, with background noise and telephone ring up louder

Table 4.6. Category: GP Referral to ORL

In this category fifteen prisoners require GP referral to specialist, tertiary level, clinical care

Number	Ethnicity	Category: GP Referral to ORL
86	Other Jordan	Moderate to severe loss both ears Hearing loss in the family Has never had hearing test done before Had noise exposure; pain and Tinnitus in right ear Yes to Dizziness/imbalance/head injury Low blood pressure Difficult to hear in all situations except one to one

Number	Ethnicity	Category: GP Referral to ORL
87	European	Slight loss right ear Moderate loss left ear Had industrial noise exposure for one year Gradual progression of hearing loss Had mild head injury Difficult hearing in groups and background noise Radio and TV up loud Sometimes misses people calling him on the phone Likes to have speakers on his right side No previous hearing assessment done
88	Maori	Severe loss in his left ear Moderate to severe loss in his right ear Previous hearing assessment No family history of hearing loss Industrial noise exposure Hearing reduced since ear cleaned out two months ago Constant Tinnitus both ears Has difficulties hearing in all situations
89	Maori	Moderate to severe loss left ear Moderate loss right ear Previous hearing assessment No hearing loss in the family No Industrial noise exposure Left ear feels like it has water in it Does not advise of hearing difficulties
90	Maori	Moderate to severe loss right ear Slight loss left ear Previous hearing assessment done Father, maternal grandmother and sister all have hearing loss Industrial noise exposure 10 years Has moderate Tinnitus in his right ear and mild in his left ear Past history of asthma Difficult to hear in groups and with background noise Needs amplification of telephone; television and radio Also has difficulty hearing sometimes at home, socially and at work sometimes

Number	Ethnicity	Category: GP Referral to ORL
91	Maori	Slight loss left ear Moderate to severe loss right ear No previous hearing assessment but knew that he could not hear well in his right ear Mother has hearing loss Industrial noise exposure Pain in his ears, itchy when blocked Intermittent Tinnitus Head Injury 2004 Has difficulty hearing in groups or with background noise and talking on the phone; radio and television are hard to hear and it is hard to hear at home and in social situations and at work
92	Maori	Profound loss left ear Severe loss in right ear Had previous hearing assessment Noise exposure Had grommets Finds it difficult to hear in groups and with background noise; telephone needs to be loud
93	Maori	Severe loss left ear Slight loss right ear Previous hearing assessment done Mother, father and sister have hearing loss Industrial noise exposure Pain in left ear Tinnitus in left ear noticeable at night Head Injury/Dizziness Hypertension Epilepsy/Asthma/Heart Murmur Can't hear when name called
94	Maori	Moderate to severe loss left ear Mild to moderate loss right ear Previous hearing assessment done Industrial noise exposure 7 years Left ear uncomfortable, not hearing Tinnitus intermittent Head injury when run over by truck 20 years ago Has difficulty hearing in groups and with background noise Uses right ear for telephone Telephone ring has to be loud Difficult to hear radio and TV and at home, socially and at work

Number	Ethnicity	Category: GP Referral to ORL
95	Maori	Moderate loss left ear Mild loss right ear No previous hearing assessment No history of hearing loss in the family Noise exposure
96	Maori	Moderate to severe loss right ear Normal hearing left ear Has history of ear infections No previous hearing assessment No hearing loss in the family Industrial noise exposure Asthma
97	Maori	Mild hearing loss in his left ear Slight hearing loss in his right ear No previous hearing assessment No history of hearing loss in the family Industrial noise exposure 7 years Dizziness Has difficulty hearing radio and television Possible right ear drum perforation
98	European	Moderate to severe loss in his left ear Borderline mild loss in his right ear Had previous hearing assessment done Industrial noise exposure Many ear infections as child Has Tinnitus right ear Knew had loss in his left ear and that he has a cyst which needs follow up Uses telephone on right ear
99	European	Moderate loss in his right ear Borderline moderate loss in his left ear Head injured as shot in left temple in Falklands War Noise exposure Gradual hearing loss Positions sound to the left side Has difficulty hearing 1 to 1; in groups; on telephone; at home; social and definitely at work

Number	Ethnicity	Category: GP Referral to ORL
100	Maori	Profound loss right ear Moderate to severe loss left ear No previous hearing assessment No hearing loss in the family Gunshot noise exposure 3 months ago Left ear perforation 3 months ago Used to hear better in left ear Intermittent Tinnitus left ear Hard hearing people on his left side When lies on right side on pillow left ear hearing dull

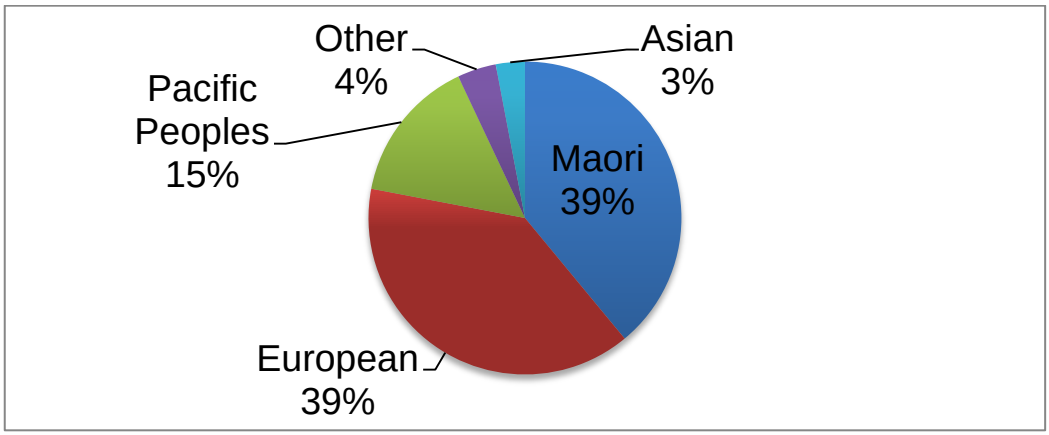
The prisoner questionnaire responses and prisoner audiogram results identify a posteriori that the prisoners who need referring to an audiologist, GP or ORL surgeon will be unable to realise their human capabilities until Serco ensures through their governance policies that these tertiary level clinical care referrals are done. If Serco does not, then, the benefit of identifying and introducing rehabilitation will be lost and the status quo will continue to prevail.

4.3.4 Summary of Prisoner Questionnaire Responses

Of the 100 hundred prisoners who were hearing screened, 24 were in the 16 to 25 years age bracket; 49 were in the 26 to 40 years of age bracket; 24 were in the 41 to 55 years age bracket and 3 prisoners were aged over 55 years. The age range of all screened was 18 to 70 years.

The prisoner's ethnicity percentages are Asian 3%, European 39%, Maori 39% and Pacific Peoples 15%.

Figure 4.1. Ethnicities of 100 Prisoners with Hearing Loss



In the Stage Two Prisoner Questionnaire prisoners were asked whether they had previous hearing assessments; whether there was hearing loss in their family and of their noise exposure and history of dizziness/imbalance/head injury.

In response, of the 100 prisoners who completed the Prisoner Questionnaire 45 reported they had been hearing tested previously and 55 reported they had not.

In Table 4.8 the prisoner responses on previous hearing testing is further analysed into five categories that define the follow up clinical management required. It is of some concern to observe that 5 prisoners who have never been hearing screened need ORL surgical assessment and that of the 37 who require audiologist referral 17 had never been hearing tested before.

Table 4.7. Number of Prisoners Previously Hearing Tested

Hearing Screening Results Category	Previously Hearing Screened	Not Previously Hearing Screened
No Further Action	6	16
Monitoring	11	15
Audiologist Referral	20	17
GP Appointment	3	2
GP for ORL Referral	5	5
TOTALS	45 Prisoners	55 Prisoners

Previous Hearing Test

Of the 52 Prisoners with hearing screening results indicating they are in need of an Audiologist referral, GP Appointment or GP visit for an ORL referral and require immediate follow-up, 22 reported there is a family history of hearing loss.

Of the 22 who reported a family history of hearing loss, remarkably, **only 7** reported receiving previous hearing tests. This is a concerning result that underscores the need for mandatory hearing testing for children and a no or low cost hearing screening programme being available to all adults.

Table 4.8. Hearing Loss in the Family

Hearing Screening Results Category	Prisoners with Family History of Hearing Loss	Prisoners with Family History of Hearing Loss who have been previously hearing screened	Prisoners with Family History of Hearing Loss who have not been previously hearing screened
No Further Action	4	2	2
Monitoring	6	3	3
Audiologist Referral	9	0	9
GP Appointment	2	2	0
GP for ORL Referral	1	0	1
Totals	22 Prisoners	7 Prisoners	15 Prisoners

Noise Exposure

In Table 4.9 the Prisoners' reports to varying types of noise exposure are categorised according to their hearing screening result recommendations and it is remarkable to note that 27 of 52 prisoners who report industrial noise exposure require audiologist referrals.

Of the 100 prisoners, 52 reported exposure to industrial noise; 4 reported exposure to other specific types of noise (3 reported loud music and one gun shots); and 18 reported exposure to non-specific types of noise exposure; 28 Prisoners did not specifically mention that they had experienced exposure to loud noise of some type. One prisoner reported in both the industrial noise category and the other specific type of noise and one other prisoner advised of exposure to both music and other noise category.

The significance of this finding is that recent research from Action on Hearing Loss (UK) indicates that noise exposure is now being recognised as a precursor to age related hearing loss. Accident Compensation Corporation (ACC), the New Zealand agency responsible for the provision of accident insurance claims which is responsible for the rehabilitation of people with industrial noise induced hearing loss will need to be advised of this finding with the recommendation they initiate a prisoner hearing screening program.

Table 4.9. Prisoner Reported Noise Exposure by Category

Hearing Screening Results Category	Industrial Noise Exposure	Non-Specific Noise Exposure	Specific Type of Noise Exposure	No Reported Noise Exposure
No Further Action	13	1	1	7
Monitoring	3	14	0	9
Audiologist Referral	27	3	2	7
GP Appointment	3	0	0	2
GP for ORL Referral	6	0	1	3
Totals	52	18	4	28

Table 4.10. Dizziness/Imbalance/Head Injury

Hearing Screening Results Category	Prisoners Reporting Dizziness/Imbalance/ Head Injury
No Further Action	11
Monitoring	8
Audiologist Referral	20
GP Appointment	2
GP for ORL Referral	5
Totals	46

The importance of the prisoner histories of head injuries is the likelihood that some of these prisoners will have undiagnosed Auditory Processing Disorder. This disorder will add significant challenges to a prisoner's successful re-integration and work placement. Prison authorities will be told of the need to do APD tests of prisoners presenting with the more obvious signs of functional deafness who have no abnormality presenting on the audiogram results.

Serco is, in the opinion of the ethnographer, beholden to provide follow up as identified as required by the hearing screening results and then it is hoped they will monitor the on-going rates of recidivism in prisoners who are given hearing loss rehabilitation. Accordingly it is pleasing to note they have advised they will continue to work collaboratively to ensure the 52 prisoners requiring follow-up are linked to the appropriate hearing health providers as their hearing test results indicates they need. They have also introduced a policy

whereby all prisoners, will be required to answer the series of questions in regards to hearing loss as outlined in Table 4.3 when completing their health questionnaire.

The Prisoner with Hearing Loss Identification project which was coordinated by the writer in the capacity as CEO of The National Foundation for the Deaf in New Zealand and PhD student from Flinders University showed very clearly the benefits of neutral, appropriately trained and skilled hearing screening professionals performing the hearing screening tests as the results were reliable and the methods used are able to be reproducible.

Also, non-government agencies such as The National Foundation for the Deaf and Life Unlimited Hearing Services who are dedicated to improving the quality of life for people with hearing loss worked collaboratively with a Government funded agency such as Serco who were committed to finding the best way to address the issue of recidivism was a successful merging of organizational aims.

4.4 Questionnaire Two: New Zealand Department of Corrections

The Department of Corrections advise on their website that they **"**work to make New Zealand a better, safer place by protecting the public from those who can cause harm [and] reducing re-offending" (Department of Corrections, 2015). With 800 staff they manage 30,000 offenders in the community and 8,500 people in prisons. Of particular importance to this research is that Corrections reports they protect the public of New Zealand from those who can harm them, by making sure prisoners, parolees and other offenders in the community comply with the sentences and orders imposed by the Courts and Parole Board and providing offenders with rehabilitation programmes, education and job training that will turn their lives around and break the cycle of re-offending.

Information about Corrections specific policies in regards to services for prisoners with hearing loss were sought from Corrections through the application of a questionnaire research tool and the questions asked were designed to ensure this occurred.

In Table 4.12 Corrections responses to Questionnaire Two are recorded. This questionnaire was designed to capture a wide view of how Corrections delivered diagnostic and rehabilitative services for prisoners with hearing loss.

Faisander introduced the ethnographer to Bronwyn Donaldson, Corrections Director Offender Health. Donaldson answered the questions in Questionnaire Two over a couple

of meetings held in Wellington. The ethnographer recorded her responses during the meetings and immediately after the meetings.

Donaldson appeared positive towards this research and keen to assist but no progress was made towards the completion of Questionnaire Two until she was directed by the Minister for Corrections to work with the ethnographer.

At the first meeting on 24 October, 2012 Donaldson verbally answered Questionnaire Two and as ethnographer the writer transcribed her answers to the template afterwards (see Table 4.1).

The writer then provided her with a copy of the completed Questionnaire Two template at the next meeting held on June 5, 2013 and she expressed surprise and concern at what she had said. Donaldson was offered the opportunity to edit Questionnaire Two if it was factually incorrect and to email the edited template back to the ethnographer. Despite a couple of reminder emails to Donaldson she did not take the opportunity to edit Questionnaire Two and the result is that the answers as published in Table 4.1 stand as correct.

Table 4.11. Questionnaire Two: New Zealand Department of Corrections Health Service

Q1. What is the NZ Department of Corrections policy on providing hearing testing for prisoners on remand?
Prisoners on remand are viewed as a higher risk of escape group and as such, are less likely to have an outside visit to an Audiologist, as they will need at least two officers to escort them.
Q2. What is the NZ Department of Corrections policy on providing Hearing testing for prisoners on sentencing?
External appointments are triaged – testing for hearing loss is way down the list as it is a non-life threatening problem. When a prisoner starts their sentence they are given a reception health triage = acute/on admission assessment. 7 days later they are given an initial health assessment – which is a wide look at the needs of “the whole person”. This is going to be moved back to day 28 and to include a mental health assessment tool too. Older prisoners are congregated together and their care is more flexible so they are more likely to get hearing tests done.
Q3. How many prisoners (as at February 1, 2011) have clinically confirmed hearing loss?

In one ear: not recorded; In two ears: not recorded. 109 prisoners listed on the Department of Corrections database have hearing loss and 500 out of over 8,000 prisoners are on prescribed medications for a range of health issues.	
Q3a. Another type of communication disorder which has recently been proven to respond, in some instances to the use of hearing aids and/or FM technology is a condition known as Auditory Processing Disorders (APD).How many prisoners have APD?	
Prisoners with APD are not identified.	
Q4. Do rehabilitation programs in New Zealand prisons now include:	
Q4a. Recognition of hearing loss? If yes, please explain how this is structured:	No, this is not formally recognised.
Q4b. Treatment of ear disease and hearing loss? If yes, please explain how this is structured and delivered?	If it is recognised, the prisoner is referred to the Health Service
Q5. If a prisoner complains of having a hearing loss how is this managed?	
They will see the Health Officer who will determine the path to take from there onwards.	
Q6. If a prisoner is recommended by a clinician as requiring hearing aids how are these funded?	
If a prisoner and their family does not have sufficient funds available the Department of Corrections will do an assessment and if need be purchase the hearing aids and require the prisoner to reimburse the Department at $2.00 per hearing aid per week.	
Q7a. If a prisoner is diagnosed as having a hearing loss what rehabilitation is offered?	
They will be assisted to buy hearing aids. A hearing therapist may also be called and asked to visit some of the prisoners.	
Q7b. Are they offered the opportunity to learn New Zealand Sign Language?	
No, they are not offered the opportunity to learn New Zealand Sign Language.	
Q8. If a primary type of communication for a prisoner is New Zealand Sign Language how is this accommodated in the New Zealand prison system?	
Some prisoners know sign language. Some prison officers know sign language but this is ad-hoc and there is no specific rostering of staff who	

can communicate using New Zealand Sign Language to work with Deaf prisoners who primarily use New Zealand Sign Language to communicate.

4.5 Questionnaire Three: New Zealand Ministry of Health

The Ministry of Health is the Government's principal advisor on health and disability with the aim of improving, promoting and protecting the health of all New Zealanders (Ministry of Health, 2015).

Information about the Ministry of Health specific policies in regards to services for prisoners with hearing loss were sought from the Ministry through the application of a questionnaire research tool and the questions asked were designed to ensure this occurred.

The response from the Ministry of Health employee was very slow to be realised and the ethnographer did endeavour to complete the questions left unanswered by the disability support sector with the Ministry's Public Health team but they were unhelpful and resistant to giving much information.

However, despite their reticence, sufficient information was received to ensure the ethnographer was able to identify whether prisoners with hearing loss were able to access State funding for hearing loss rehabilitation through the Ministry of Health Disability Support Services, which informed the ethnographic policy review process at hand.

The Newborn Hearing Screening Programme is offered to all newborn babies in New Zealand. This is a by guardian or parent consent programme and there is no mandatory component. There is no mandatory hearing testing in children or adults. This stance aligns with all other State funded health testing programmes in New Zealand as none are mandatory. This respects the Universal Declaration on Human Rights where an individual has the right to choose and also sits well with the Government health and well-being budget holders as less services will be accessed when they are on mandated thus incurring a lower cost on the public purse.

Table 4.12. Questionnaire Three: New Zealand Ministry of Health Questionnaire Response

Q1. Screening for Hearing Loss **a) At what age/s is hearing screening done in New Zealand?** **b) Is hearing screening mandatory in New Zealand?**
Newborn Hearing Screening Programme is offered to all newborn babies in New Zealand. This is a by guardian or parent consent programme and there is no mandatory component. There is no mandatory testing in either children or adults.
Q2. What is the Ministry of Health Policy on funding of: **a) Hearing loss prevention programs?**
The Ministry of Health does not have a policy on hearing loss prevention. These services tend to be delivered by District Health Boards.
a) Diagnosis of hearing loss?
The Ministry does not provide direct funding for the diagnosis of hearing loss. District Health Boards (DHBs) are funded through the Crown Funding Agreement to provide audiology services - the nature of their services is determined by individual DHBs. Hearing therapists, who have a Ministry contract, undertake hearing evaluations. The Ministry does not provide designated funding towards the cost of hearing tests through audiology services (public or private).
a) Rehabilitation for people with hearing loss?
For adults aged 16 years and over (as this research is targeted towards the needs of prisoners who have a hearing loss) rehabilitation services are provided through Hearing Therapy Services. This service, contracted by the Ministry, supports people in the following ways: • Help people use their hearing more effectively • Teach ways of improving their communication skills • Help people use hearing aid(s) to greater effect • Give information about equipment available to assist with daily living, e.g.; telephone, television • Offer information and advice to people and their families • Teach speech reading and provide auditory training • Offer advice, practical help to people with tinnitus • Provide information about hearing loss and its prevention to professional groups, community organisations and the general public. In addition, rehabilitation programs are funded through the Ministry's contracted cochlear implant trusts for people following provision of a cochlear.
Q3. How much does the Ministry of Health spend on: **a) Hearing loss prevention programs?**

This question would need to be answered by the Ministry's Public Health team.
b) Detection and diagnosis of hearing loss (cost by programme please)?
This is not applicable to Disability Support Services.
c) Rehabilitation for people with hearing loss?
The current value of the Ministry's contract for hearing therapy services per annum is $2,391,086.
Q4. Who is responsible for the delivery of Ministry of Health funded hearing loss rehabilitation services to prisoners?
Prisoners are considered to be service users in the same way non-prisoners are. Hearing Therapists may visit prisoners on occasion when they have been referred for services, or prisoners may be escorted to the Hearing Therapist's premises to receive support and advice. Prisoners would also be eligible to receive support through their local DHB audiology services where the DHB provided services for adults with a hearing loss.
Q5. Is there a process whereby the Ministry of Health and the Department of Corrections communicate to identify the annual rehabilitation needs for prisoners with disabilities, in particular prisoners with hearing loss? Please advise:
No formal communication occurs between representatives of Disability Support Services and Corrections at this time.
Q6. Who audits the delivery of the Ministry of Health contracted hearing loss rehabilitation for prisoners? Please advise:
No specific audit of services for prisoners is undertaken as they are considered to be consumers of services in the same way as other members of the community.
Q7. How many people, in total, use the Ministry of Health funded hearing disability rehabilitation services?
7,213 people accessed Hearing Therapy Services in 2012-13 (noting some people may be counted in more than one quarter). Please note that figures for cochlear implant services are not included here.

4.6 Policy Implications

The policy implications will be discussed in-depth in chapter five, however a brief snap-shot of these questionnaire findings from both Corrections and the Ministry of Health show a blatant disregard for the human rights of prisoners with hearing loss, in particular CRPD

Article 9 - Accessibility. There is a real need for both organisations to actively promote the realization of the potential human capabilities of prisoners with hearing loss.

To address the issue of marginalisation there needs to be a strategic response by Corrections, Serco, the Department of Justice and the Ministry of Health to recognise the needs of this group of vulnerable and at-risk prisoners and actively state in their policies that this group will take a higher policy recognition when allocating funding to achieve rehabilitation and societal re-integration and avoid recidivism.

Furthermore, it is being reported that 17% of children in New Zealand have at least one parent who is actively engaged with Corrections either as inmates or on community sentencing. These children are now being recognised as the most at-risk of following in the footsteps of their parent/s. It is these children who need targeted, wrap around support from health and social services to give them the opportunity to have positive life outcomes. These recommendations will be explored further in chapter five.

CHAPTER FIVE

LEADING THE CHANGE

The key issues as identified throughout this research are the lack of mandatory hearing screening and the impact of this on New Zealand children; the ineligibility of prisoners with hearing loss to gain funding support through the Ministry of Health Hearing Aid Funding Scheme (HAFS); the lack of screening for Auditory Processing Disorder in prisoner populations; the uncertainty of whether prisoners with severe to profound hearing loss are eligible for State funded cochlear implants and whether prisoners can access ACC funding of rehabilitation for Noise Induced Hearing Loss. The Government policy on these issues will be examined further on in this chapter.

In this chapter policy analysis will be done, which will examine the available resource allocation by public officials who are endeavoring to achieve specific goals when they make their decisions.

Then, two further policy areas for consideration are the need for captioning to enable access for people who are hard of hearing who cannot do New Zealand Sign Language as they track through the judicial process and the hearing status of the 17% of children who have parents either in prison or serving community based sentences, as hearing screening needs to be done for every child who has a parent “in the system”.

The writer also takes this opportunity to raise a flag of concern on the need for the Government policy for funding of unilateral cochlear implants for children to be reconsidered and the situation for bilateral cochlear implants for adults, as a means to prevent marginalisation and loss of social status. These two policy issues relating to cochlear implants are mentioned as they are both recognised as important by t he writer but are outside the scope of this research excepting whether prisoners are eligible to receive cochlear implants.

To recap, of the 52 prisoners who were confirmed by testing as needing further audiological or clinical services, 4% were Asian; 37% were European whilst 42% were Maori; 15% were Pacific People and Other comprised 2%. In this small group who self-referred for hearing screening both Maori and Pacific People were significantly over-represented. Although this is not conclusive due to the small number of prisoners being

tested, these results clearly indicate that hearing loss needs to be considered and addressed as an issue when a prisoner's rehabilitation and reintegration programme is being developed.

A range of cases as reported below highlight that hearing loss was present before incarceration; in some instances, family histories were remarkable in that there was a high occurrence rate of hearing loss; that Secretory Otitis Media (Glue Ear) and head injuries were evident too. All of these indicators should have been sufficient for prison health professionals interacting with these prisoners to recognise there was an issue with hearing loss and require hearing screening to be done. But they did not.

Case study 1 (Ch.4, Table 4.4, #75)

In answer to whether there was a family history of hearing loss one prisoner responded that his mum, uncle and nieces all have hearing loss but he had never been hearing screened before. When he was screened to check his hearing his audiogram results showed a borderline moderate hearing loss in one ear and moderate hearing loss in the other that had not been previously detected. He had difficulty hearing in groups and with background noise and also suffered from Tinnitus.

Case Study 2 (Ch.4, Table 4.4, #73)

As a truck driver he was exposed to noise for 19 years but he has never been hearing screened. His hearing screening results showed he has a moderate to severe hearing loss in one ear and severe hearing loss in the other ear. His family history shows his daughter has hearing loss. He complained of throbbing inside his ears and also suffered from Tinnitus. In addition he had a head injury in 1980's. He finds it difficult to hear in groups and with background noise, to hear socially and at work. The Hearing Therapist wrote on his questionnaire that he "[c]an't distinguish what is said."

Case Study 3 (Ch.4, Table 4.4, #69)

Although he was exposed to power tools his audiogram hearing screening results showed only a slight loss of hearing however he had an impressive history of head injuries as reported by the Hearing Therapist who wrote he has "[b]een in lots of fights & knocks to the head and injuries too, car accidents as well." He advised of difficulty hearing in groups and background noise and listening to the radio and television. This prisoner is being

referred to an audiologist with the recommendation that he may need screening for Auditory Processing Disorder.

Case Study 4 (Ch.4, Table 4.5, #84)

He had grommets put in his ear drums for ‘Glue Ear’ when at primary school. His brothers and cousins all needed them too. He noticed he had a hearing loss in his teenage years and has a moderate loss in one ear and a lesser loss in the other. He uses his left ear to hear on the telephone and sometimes finds it hard to hear at home, at work and socially. He needs his television and radio up louder than other people.

Case Study 5 (Ch.4, Table 4.6, #98)

His brain scan done some years earlier “identified a cyst” that had not been followed up and his hearing screening results showed a severe hearing loss in one ear. This prisoner appears to have fallen into a follow-up gap, which is often observed in transient populations and it was recommended that he needs a General practitioner referral to an Otolaryngologist (Ear Nose and Throat surgeon).

5.1 Summing up

In chapter one an overview is given on the research issue, aim and design were defined, as were the New Zealand prison environment and as well, the policy makers probable response to the recommendations that will be outlined in this chapter. Then, the Human Capabilities Approach and the theory of social contract were both examined in chapter two from the perspective of how they could apply to prisoners with hearing loss, followed by an examination of various pertinent New Zealand Acts and UN Conventions, analyzing them to understand if they legally mandate hearing health care for prisoners nationally.

In chapter three, consideration was given to the multi-method qualitative research models and the prisoner research was framed using Fetterman’s ethnographic life-stages framework and in chapter four statistics applied globally were investigated and reported as were the three questionnaire results, from prisoners, Corrections and Ministry of Health questionnaire.

Both weaving through and underscoring this analysis was the lived experience of learning about policy which led to the autoethnographic advocacy practices of changing it to relieve human suffering.

5.2 Policy Design

When designing policy, consideration as to whom the policy will impact on; the purpose of the policy; how to recognise the success or failure of the policy design; who makes the decision on the policy design and funding stream allocation; what factors or conditions are outside of their scope for decision making and what part of the successful planning and implementation of the system is within their scope all need defining.

Then, identification of who the planners and experts are as well as understanding their area of expertise and who represents the interests of the affected, who are not necessarily involved, a good example of which is prisoners with hearing loss. There is also a need to define if people with hearing loss are given an opportunity to express their concerns on an equal basis with the recognised experts that are consulted with by the policy developers.

5.2.1 Lack of Mandatory Hearing Testing

This research design was initially directed towards understanding if the recommendations from Bowers' research were implemented; if the impact of ear disease and or hearing loss was a recognized causal factor to anti-social and possible criminal behaviours; how this disability is being detected and managed by the New Zealand Department of Corrections when prisoners are incarcerated and if prisoners with hearing loss are marginalised or offered support to achieve equity with their hearing abled prisoner peers.

It is important to recognise that Bowers' recommendations have been partly implemented through the application of the non-mandatory New Born Hearing Screening Programme, which the implementation of was primarily advocated for and driven by a group call "Project Hiedi" who were aligned with The National Foundation for the Deaf.

However, tragically, Bowers' recommendations in regards to the detection of hearing loss in prisoners have fallen on deaf ears at Corrections. Accordingly, when considering the voice and needs of prisoners who are hard of hearing, the New Zealand Government does not acknowledge their need for hearing screening, or hearing rehabilitation and disability support for reintegration when released back into society. This really is a wicked problem that both the New Zealand Minister and the Department of Corrections need to urgently address.

This journey of discovery has shown that Bowers' recommendations were not fully implemented and that presumed prisoner marginalisation due to hearing loss continues unabated in New Zealand prisons. In fact, it has increased, as prisoners are now unable to

vote in New Zealand's General Election after they are convicted and their right to democratic participation is denied until they are released from prison.

5.2.2 Ineligibility of Prisoners to Gain Funding from the Ministry of Health Hearing Aid Funding Scheme

When incarcerated in the public Government managed prisons, prisoners are assessed for risk, needs and responsivity and the data is gathered through a centralized reporting system. This data is then used to predict recidivism potential and rehabilitation needs of all prisoners. From this data collection it has been identified that 84% of prisoners have literacy and numeracy deficiencies; 50% have a reading age of less than 9 years and 68% have addiction issues. These are alarming statistics which reflect that many in our prison populations are the most vulnerable in society (Lynds, 2013) and in recognition of this, there are on-going active interventions to address challenges such as Dyslexia in prison populations however the same cannot be said for hearing loss.

But, urgency needs to be applied in this regard as many people who develop hearing loss after developing oral language do consider the impact of losing part or all of their hearing to be disabling and the provision of rehabilitation support and equipment to be enabling and essential for them to achieve social integration thereby decreasing marginalisation.

To achieve integration with the hearing abled, most people who are hard of hearing positively support and use medical technological advances such as hearing aids; loop systems; FM remote microphones and cochlear implants. They consider this technology decreases marginalisation and increases quality of life and social integration. To be able to achieve the same level of functional independence, employment and social integration after release from prison, prisoners with hearing loss also need to be able to access this technology as part of their pre-release rehabilitation and recidivism prevention programme.

Thus, the next point for consideration is the funding of technology for people who are hard of hearing and whether this funding is available through policy for prisoners who are hard of hearing. In Table 5.1 ethnographic investigations determine that over $31,000,000 of tax-payers funds are applied per annum by the Government to the rehabilitation of hearing loss in New Zealand.

Table 5.1 shows that the Ministry of Health significantly funds neonatal and pediatric hearing loss detection and rehabilitation support programmes thereby meeting much of the demand in the pediatric population.

But, there is one group of children who have functional deafness that the Ministry of Health has devolved the funding responsibility for their rehabilitation to the Ministry of Education. These children, who have conditions that fall within the scope of an Auditory Processing Disorder diagnosis (APD) often require rehabilitation therapies including the provision of hearing aids for the child to wear and a remote microphone that is worn by their classroom teacher to ensure a directed high quality level of sound is transmitted to their hearing aids.

However, the Ministry of Education policy is to only fund equipment for children with APD if they are failing to achieve national educational standards, refusing instead to fund this equipment on audiologist clinical diagnosis and rehabilitation recommendation. Also, as the hearing aids and remote microphones are considered the assets and property of the school that funds and insures them, some schools will only allow children with APD to wear them at school, during class sessions.

Considering that children with disabilities have been identified by UNESCO as being at higher risk of all types of child abuse, the notion that a child with deafness is not being allowed to use essential rehabilitation equipment that will assist them to achieve social integration is quite repugnant. The National Foundation for the Deaf has taken this matter to the Minister for Education and she advises that the decision in this regard sits with the Principal of the schools concerned. Parents are now being forced to seek the Principals permission to ensure their child who has functional deafness is permitted to use their hearing aids and remote microphones outside of class time (Esplin & Wright, 2014).

The National Foundation for the Deaf has done extensive advocacy work on this and a number of matters related to the needs of children with APD and as well, supported a new family support and advocacy national organisation, called Hear for Families, to become established.

The extensive advocacy work done by the hard of hearing sector in advocating for the rehabilitation needs of these children to be recognised and met has resulted in the establishment a Government Auditory Processing Disorder National Expert Advisory Group by the Ministries and of Health and Education, with the writer appointed as the member with Human Rights responsibilities. Though it has taken four years to achieve, the release of the draft national guidelines on Auditory Processing Disorder is imminent. The process applied to achieve this level of policy definition and intervention follows the model of the “policy community” (Colebatch, 2005, pp. 15-16) which is a group of organized

voices coming from a range of perspectives who are able to contribute even though their contributions may offer conflicting advice.

Having considered the pediatric sector, the situation with adults who are hard of hearing and require rehabilitation needs examining further through the unpacking of the application of one of the programmes outlined in Table 5.1. This may offer some understanding as to why there is still a significant amount of unmet hearing loss rehabilitation need in the New Zealand adult hard of hearing sector. The programme for in-depth consideration is the funding and provision of hearing aids through the Hearing Aid Funding Scheme (HAFS) for adults with hearing loss.

Table 5.1. Ministry of Health Funding

As outlined in Table 5.1, $7,018,446 of tax payer contributions were allocated through Vote Health to HAFS from 1 July 2013 to 31 June 2014.

Ministry of Health Programme	**2013/2014 Funding**
Well Child Tamariki-Ora Programme (includes non-mandatory Newborn Hearing Screening plus hearing tests at ages 8-10 weeks; 5-7 months; 9-12 months;15-18 months; 2-3 years and again in the B4 School check at 4 years	$10,988,940.00 (funding partially applicable to hearing loss detection programme)
Hearing Aid Funding Scheme (HAFS)	$7,018,446
Hearing Aid Subsidy Scheme (HASS)	$9,409,230
CI's Adults Waiting List (deaf)	$1,811,360 $1,800,000
Paediatric CI's (deaf)	$1,268,744 $6,000,000
Cochlear Implants – child or adult (children get priority)	$1,900,000
Cochlear service funding – existing service users (child and adult)	$2,407,896.

An examination of the policy shows that HAFS pays for hearing aids for children and adults who are both Deaf and Hard of Hearing nationwide as it "covers the cost of hearing aids for eligible children and adults who are New Zealand citizens living in New Zealand or who are permanent residents. Adults are eligible if they:

- have had a significant hearing loss from childhood, or
- have hearing loss and a significant visual impairment (for example, Deafblind); or hearing loss and an intellectual disability or a physical disability that limits their ability to communicate safely and effectively, or

- have a Community Services Card and are:
  + in paid employment for 30 hours per week or more, or + a registered job seeker seeking paid employment, or
  + doing voluntary work (more than 20 hours per week), or + studying full time, or

- + caring full time for a dependent person."

  (Ministry of Health, 2012)

Accordingly, prima facie, the first part of the HAFS policy could apply to prisoners with hearing loss if they have been identified as having a significant hearing loss early in life or have co-morbidities such as a significant hearing loss and mental health issues. But, as seen in the hearing screening results of the 100 prisoners tested, some prisoners have never been hearing screened and their status in regards to the first part of this policy would be uncertain. In regards to the latter part, prisoners are ineligible and cannot apply for a Community Services Card thus this section of the policy cannot apply.

This in-depth consideration of the HAFS policy shows that prisoners are very likely to be ineligible to receive Government funding of hearing loss rehabilitation services through HAFS. It also shows that the policy developers did not consult with prisoner advocates and that marginalisation of this group is entrenched in policy development and implementation and needs challenging.

In regards to access to the Ministry of Health funding for cochlear implants, an enquiry to the Northern Cochlear Implant Programme shows there is uncertainty on whether prisoners can access funding for cochlear implants and the writer is awaiting their further advice in this regard.

Examination of the policies of the other three Government agencies providing hearing aid funding was done to identify if prisoners with hearing loss are ineligible for funding and support from other hearing loss rehabilitation services too.

In total, four Government agencies fund hearing aids in New Zealand. Audiologists who are members of the New Zealand Audiological Society (NZAS) and apply their Code of Ethics are able to prescribe hearing aids and apply for payment on behalf of their clients to these Government agencies.

If an Audiologist is not a member of the NZAS they are unable to apply for funding from the following four Government agencies to help with the cost their clients have to pay when purchasing hearing aids.

The first Government agency is the Accident Compensation Corporation (ACC); the second being the Ministry of Health; third is Veterans Affairs for armed forces personnel and the fourth is the Ministry of Education who fund hearing aids with remote microphones for use at school by children with APD (functional deafness).

The ACC offers support in three bands for monaural (one hearing aid for hearing loss in one ear) and binaural (two hearing aids for hearing loss in two ears). Binaural use of hearing aids is preferential as it avoids the risk of the unaided ear developing the auditory deprivation effect and keeps hearing active in both ears. The cause of the auditory deprivation effect is a lack of sufficient stimulation of the hearing nerves, which slowly becomes weakened from underuse. As an individual with hearing loss the writer much prefers to wear two hearing aids as it enhances the feeling of balanced hearing which is far less demanding on sound processing when understanding human speech and on sound direction identification (Healthy Hearing, 2010; Kochkin, 2015).

The determination of eligibility for each ACC funding band which is based upon the degree of hearing loss with the higher rates of hearing loss being eligible for the higher bands. Monaural payment bands are Band I $526.70; Band II $1053.40 and Band III $1756.05. Binaural payments are Band I $1053.40; Band II $2106.80 and Band III $3512.10.

But, in conversation with Anne Greville, ACC Audiology Adviser (28/11/14), she advised that ACC does not fund hearing aids for prisoners because the ACC Act 2001 ("ACC Act," 2001) does not permit this. However, prisoners are permitted funding for injury treatment and rehabilitation, both of which are descriptors that can apply to injury caused hearing loss including Noise Induced Hearing Loss and head injury caused Auditory Processing Disorder. This appears to be in conflict with the advice from Greville and clarity will be achieved through further enquiry and advocacy with ACC.

Veterans Affairs funds $1897.50 per hearing aid and $3277.50 for two, whereas the Ministry of Health funds through a different model again. They have two brackets for funding, one being the Hearing Aid Funding Scheme (HAFS) where the full wholesale price is paid for the hearing aid, and the other being the Hearing Aid Subsidy Scheme (HASS) where they subsidize the cost.

If the circumstances of a person who is hard of hearing fits the terms of the Hearing Aid Funding Scheme (HAFS) policy they are able to gain full (wholesale) funding of their hearing aids, which are then fitted by their local District Health Board (DHB) (providing that

the DHB chooses to deliver an audiological service). If a person with hearing loss does not fit the policy conditions of the HAFS policy as outlined above, they will most likely be eligible for support from the Ministry of Health Hearing Aid Subsidy Scheme (HASS).

The HASS "provides $511.11 (including GST) per hearing aid to adults (over the age of 16) who have a permanent hearing loss and need a hearing aid, are New Zealand citizens living in New Zealand or permanent residents who are not covered under the Hearing Aid Funding Scheme…. The [HASS] subsidy for each hearing aid is available no more than once every six years." (Ministry of Health, 2012)

> "District health boards (DHBs) are responsible for providing or funding the provision of health services in their district. Disability support services and some health services are funded and purchased nationally by the Ministry of Health" (Ministry of Health, 2015).

There are 20 DHB's and audiology services are Ministry of Health bulk funded without specific audiology service reporting requirements in their Ministry of Health contractual obligations. This non-specific reporting permits a lack of transparency, in particular, on audiological service delivery.

Its impact can be seen when considering the delivery of services for people who are hard of hearing and eligible to receive fully funded hearing aids (paid at wholesale rates) through the Ministry of Health Hearing Aid Funding Scheme (HAFS). For HAFS approved clients, the Ministry of Health requires DHB Audiology services to provide hearing aid fitting and hearing rehabilitation services, which are required to be done at no cost.

But this lack of transparency through contract reporting has enabled "73% of DHB's to place restrictions on access to their audiology services such as the holding of a [Community Services Card and for] …13% of" the 15 respondents out of 20 DHB's surveyed in 2014," to, with impunity, cease delivering audiology services altogether (Wallace, 2014, p. 7).

The National Foundation for the Deaf has received requests for assistance from people who are approved for HAFS funding and been referred to their local DHB for hearing aid fitting and rehabilitation services. However, when contacting their local DHB they have been advised there is no audiological service available to meet their needs. They are then referred to and are required to purchase hearing aid fitting and rehabilitation services from private sector retail outlets, which can incur a cost of $150 to $700 (Wallace, 2014).

This occurs because the Ministry of Health does not fund the service fee component of HAFS for those who are eligible to receive the wholesale priced hearing aids as the DHB is expected to cover the cost of delivering services such as fitting hearing aids and other hearing loss rehabilitation requirements. But, people with hearing loss who are eligible for HAFS are rarely able to fund private sector costs of their hearing rehabilitation and hearing aid fitting costs.

Though eligible for HAFS funding of hearing aids and rehabilitation, if their DHB does not provide the necessary service delivery component, then those in the highest need, which is a bracket many prisoners who are hard of hearing will sit within at prison release, must go without their vital hearing loss rehabilitation including hearing aids.

This is an unacceptable situation that has been able to evolve because of the lack of transparency on DHB service delivery. As such, it really does require immediate intervention to correct this policy anomaly and service delivery gap. It also highlights the very real need to include specific audiological service measurements in the DHB Ministry of Health contract reporting, allowing the Ministry of Health Disability Support Service policy staff to see the DHB audiological service delivery gaps.

From the different rates of payments, as previously outlined, it is reasonable to conclude that considerable inequity exists between three of the four funding streams for hearing loss rehabilitation including technology, with the fourth which is that of the Ministry of Education funding for children with APD being inaccessible unless a child is failing educationally.

There is also evidence of a significant decline in DHB audiological service outputs, which is compounded by a lack of transparency in service delivery reporting to the Ministry of Health.

Given this set of circumstances, there is a real need for a National Deafness Advisory Group to be established to give quality advice to Government policy developers at all levels ensuring equitable funding and enabling the development of appropriate service delivery for all citizens with hearing loss, whether they be incarcerated or not.

5.2.3 Need for Prisoners to have Auditory Processing Disorder Screening

Purdy, S. (University of Auckland) presented at the New Zealand Audiological Society in 2013 that a cohort of over 900 Pacific Island children being longitudinally studied by the University of Auckland, were tested for APD at the age of 12.This is the age that it would

be evident by if their brains were going to maturate and the APD would no longer be an issue. Purdy identified that at least **35.5%** of the children still had APD. Purdy's results are very concerning.

In addition, the prisoner responses to the Stage two Prisoner Questionnaire show that of 100 prisoners with hearing loss over 60% report some type of head injury. This too is very concerning and indicates there is an evidence base for the statement there is a need for prisoners to be tested for APD.

Auditory Processing Disorder (APD) is a functional loss of hearing that does not present as a hearing loss on an audiogram. "The American Speech Language Hearing Association (2005) and the American Academy of Audiology (2010) define APD [as:]…difficulties in the perceptual processing of auditory information in the central nervous system and the neurobiologic activity that underlies that processing and gives rise to the electrophysiologic auditory potentials. The definition of the Committee of UK Medical Professionals Steering the UK Auditory Processing Disorder Research Program states that…:"APD results from impaired neural function and is characterized by poor recognition, discrimination, separation, grouping, localization, or ordering of speech sounds. It does not solely result from a deficit in general attention, language or other cognitive processes." (Keith, 2015) (Sound Skills, 2013).

> Adults presenting with suspected Auditory Processing Disorder may have difficulty "paying attention to and remembering information presented orally**…**carrying out multi-step directions**…**[have] poor listening skills….[and n]eed more time to process information." As well, they may have faced significant challenges with learning reading, comprehension, spelling, and vocabulary and were considered to have had behavioural problems if the APD was present during childhood (Additude, 2015).

It is reported that causes of APD in childhood include birth-related factors, hereditary factors, Otitis Media in infancy or early childhood, or brain maturational delay.

On considering the life-path of prisoners, it is reasonable to believe some may have had untreated Otitis Media as infants and children. If this occurred during critical neuro-developmental time window the lack of auditory stimulation can mean that the hearing pathways in the brain did not develop normally. As reported by Dr. Bill Keith of Sound Skills, which is a private APD diagnostic and treatment center in Auckland, "there is some research evidence to show that prolonged otitis media (of which glue ear is a common form) can result in APD, presumably because hearing has been disrupted during important developmental periods."

In addition, APD in adults can occur secondary to a brain insult such as a head impact in a car accident or from neurotoxicity through chemical events from both prescribed and illegal substances. Prisoners could have multi-factorial reasons for having APD including prolonged maternal deprivation during pregnancy; chronic Otitis Media as an infant or child; brain insults in events such as domestic violence incidents or from neurotoxic events from substance abuse.

These life events in prisoners could have caused a dysfunction in any of a number of hearing pathways, circuits and centres in the brain. Each case of APD will have its own pattern of disordered function such as being unable to recall and repeat very simple musical patterns of high and low pitch notes or recognise the directional or spatial hearing and the related ability to hear against background noise.

There are also various types of APD hearing loss that will significantly impact on prisoner employment opportunities, such as being unable to hear very fast changes at the start of speech which can affect a person being able to correctly hear sound. As well, auditory attention which is defined as being able to concentrate and maintain attention on incoming information and remembering what has just been heard can be impaired and is yet another type of APD. In addition, recalling through auditory memory the order of the sounds heard and correctly identifying and discriminating between speech sounds are further types of APD that prisoners can present with.

In addition to non-audiogram hearing functioning tests, some differences in brain function can be seen in prisoners who have APD through objective physiological tests such as decreased neurological activity on Functional Magnetic Resonance Imaging (FMRI) and as delayed electrical responses to certain speech sounds at the cortex of the brain, which is known as delayed cortical responses.

At present, as confirmed in the responses to the Ministry of Health and Corrections Questionnaire responses in chapter four neither Ministry has a policy on the testing of prisoners to determine if they have APD. It is expected that, the policy advice about to be released by the New Zealand APD Expert Reference Group will support the development of appropriate, evidence based, APD pediatric and adult services.

Membership of the APD Expert Reference Group includes the writer in the role of an adult with APD and also with human rights responsibilities, a parent of three children with APD, a Professor of speech language from the University of Auckland, an audiologist working in

the DHB sector and a senior APD rehabilitation practitioner working in the for profit sector. Also, on the Group are middle-level bureaucrats from the Ministries of Education and Health. Thus, the concerns of people with APD are well-represented by those who have the condition and by those involved in proposing policy content that will drive service development.

It is vital that the service development proposed by the APD Expert Reference Group is challenged to consider how the draft policy will be extended to accommodate marginalised groups such as prisoners and harder to access indigenous populations.

5.2.4 Captioning to ensure Access to Justice

Access to justice is a human right recognised in Articles 5.1, 7, 10 and 12.3 of the Universal Declaration of Human Rights. These rights are further implemented through Article 13 of the Convention on the Rights of Persons with Disabilities (CRPD). The CRPD is incorporated into New Zealand law through the New Zealand Bill of Rights 1990 (BORA). The relevant BORA Articles 23, 24 and 27 pertain to a prisoners' right to attain justice.

Article 23 (1) states that "Everyone who is arrested or who is detained under any enactment –

> shall be informed at the time of the arrest or detention of the reason for it;"
>
> Article 24 states that "Everyone who is charged with an offence –
>
> shall be informed promptly and in detail of the nature and cause of the charge;…
>
> (g) shall have the right to have the free assistance of an interpreter if the person cannot understand or speak the language used in court"
>
> Article 27 legally mandates the "Right to Justice
>
> (1) Every person has the right to the observance of the principles of natural justice by any tribunal or other public authority which has the power to make a determination in respect of that person's rights, obligations, or interests protected or recognised by law.

Being able to access captioning or sign language through a New Zealand Sign Language interpreter is essential for prisoners with hearing loss enabling them to knowingly participate in the judicial process. At the Foundation we know that some prisoners with hearing loss have been unable to access justice because of their inability to fully understand proceedings.

This writer cannot over emphasize how vital it is for a prisoner with hearing loss who is attending meetings and hearings that will have impact life-long, at Corrections, the Justice Department or the Department of Courts, to have access assured through the provision of a Captioner or a New Zealand Sign Language interpreter.

In New Zealand, there are only three professional Captioners, two of whom work in the Auckland region. In a recent discussion with the Captioner who works in the hearing loss sector the writer asked her if she had done captioning for prisoners at Corrections, the Justice Department or the Department of Courts. She responded that she had only been called into Mt Eden Corrections Facility on one occasion, but this was because the legal Counsel had hearing loss, not the prisoner.

When all three Government departments fail to provide a Captioner or a New Zealand Sign Language interpreter then the human rights, as defined above, are being abused.

As briefly mentioned in chapter 4, the Foundation has been approached by individuals, who have hearing loss and consequently have been denied access to the judicial process. This is because of their inability to fully hear and understand proceedings. We know of a Deaf teenager who was imprisoned without knowing why; an adult with APD who did not understand the Family Court processes and another who did not understand the Criminal Court processes. The point of commonality in all of these cases is that access to justice through communication support by using technology such as hearing aids with remote microphones, captioning or the skills of a New Zealand Sign Language interpreter have been denied.

The writer was recently advised by a Member of Parliament that the CEO's of Corrections, Serco, Justice Department and the Department of Courts meet regularly as a Group. It is the writers' intention to ensure that all are made aware of the consequences of failing to uphold the prisoner's right to access justice and the need to develop a policy on this vital matter. They will be advised, given the extent of prisoners who have hearing loss and history of head injuries, in combination with the findings of Purdy et al, that it is reasonable to believe human rights breaches are occurring on a daily basis in all of their institutions and facilities.

5.2.5 Hearing Screening of the 17% of Children who have Parents as inmates or serving a Community Sentence

The writer attended recent presentations done by the Hon Bill English, Deputy Prime Minister at the JR McKenzie 75th Anniversary Dinner held at the Grand Hall, New Zealand Parliament Buildings in Wellington on November 18, 2015, and the Hon Amy Adams at the 2015 Captioning Awards Event held on November 27, 2015 at the Langham Hotel in Auckland. As guest speakers' they both spoke about the need to identify the children whose parents were known to Corrections and Serco either as prison inmates or serving Community Sentences because these children are now being recognised as the most at-risk of becoming the next generation of 22,000 offenders who go through the New Zealand penal system on an annual basis.

It is now recognised that these children require a wrap-around social service to ensure they are appropriately and positively supported to choose an alternative life-path. Given the high rate of hearing loss being recognised in prisoners globally it is imperative that these children have regular hearing screening done and rehabilitation given at the first indication of any hearing issue being identified.

The writer will ensure the Minister of Social Development is advised of the need for regular hearing screening to be included in any diversionary programme established for these children.

5.3 Policy and Governance Recommendations

This research design was initially directed towards understanding if the recommendations from Bowers' research were implemented as they would have addressed the issue of hearing loss causing prisoner marginalisation. It was also developed to define if the impact of ear disease and or hearing loss was a recognized causal factor for anti-social and possible criminal behaviours and how this disability is being detected and managed by Corrections when prisoners are incarcerated.

The recognition of hearing loss as a causal factor for anti-social and possibly criminal behaviours remains unproven. However, from having lived experience on the impact of hearing loss the writer believes that the sheer frustration of having repeated communication failures can lead to these mistaken beliefs occurring and then people with hearing loss are further marginalised as a result.

The recommendation is that Corrections asks every prisoner about the status of their hearing and then, does hearing screening for all who are unable to positively answer the questions as asked. As identified in chapter 4, there is a posteriori showing emerging areas of concern, that could be proactively addressed and areas of hearing loss that show a more defined opportunity to increase the human capabilities of the affected prisoners.

These reflect there is a need for Serco in their governance role to be proactive in their response by introducing in their governance a policy on hearing screening practices. This would introduce hearing preservation as a preventative measure in the prisoner well-being programme thus enhancing prisoner human capabilities.

Corrections is in a position where they can positively and legitimately influence the life journey for our most marginalized citizens. Accordingly, consideration needs to be given to the development and piloting of a comprehensive strengths based capabilities programme using a health and well-being screening tool which recognises what prisoners are able to do within their current situation and what they would like to be if their situation was enabled.

Rather than asking the prisoner questions to identify what is wrong with their ability to function as the current prisoner health questionnaire does, the writer recommends that a strength based approach be used. The “[s]trengths-based approaches concentrate on the inherent strengths of individuals, families, groups and organisations, deploying personal strengths to aid recovery and empowerment. In essence, to focus on health and well-being is to embrace an asset-based approach where the goal is to promote the positive.” (Iriss, 2012).

As the strengths based approach is goal oriented, the goals can be set in collaboration with the prisoner helping to determine what they would like to achieve in their life, which aligns well with the Human Capabilities Approach of identifying what a person is able to do and be.

Using one of the strengths based management tools, of which there are a number of models to choose from, the prisoner will be collaboratively assessed with the aim of identifying the resources they already have available and to identify the links needed to ensure the activation of these resources. It is essential to include access to culturally appropriate communication modalities including Captioning; English New Zealand Sign

Language (bi-lingual interpreters), with Maori signing as required (tri-lingual interpreters); Pacific Island, Asian and other languages as needed.

The writer has often used this approach as it is hope-inducing and relationships with cultures and communities are strengthened. It is also respectful of the fact that an individual is an expert on their own life-path and it can positively support a prisoner to make appropriate life decisions and possible changes.

This approach would also include asking each Prisoner what they are able to do and use that as a starting point to evaluate what their needs actually are, showing what a prisoner can and is able to do rather than only being driven by fund holding and social harm prevention.

The headings on the Prisoner heath questionnaires (the MOI) used for remand and sentenced prisoners could be the capabilities as defined by Nussbaum: life; bodily health; bodily integrity; senses, imagination and thought; emotions; practical reason; affiliation; other species; play; control over one's environment both politically and material. (Nussbaum, 2006, pp. 76-77).

Serco is alert to this possibility and in addition to the project done at Mt Eden Corrections Facility, they have now inserted the questions (Ch.4, Table 4.1) into their Prisoner Health Questionnaire. Corrections is yet to step up.

In the capacity as a Board member with Human Rights responsibilities for the International Federation of Hard of Hearing People (IFHOH) the writer has been the facilitator for discussions underway with the Deafness Forum of Australia in regards to the implementation of a similar research project at a Serco facility in Australia. This project is still on the table and will be discussed further in 2016. If done, the research findings between New Zealand and Australia will then be compared and contrasted.

5.3.1 Democratic Process Marginalisation

It is evident that marginalisation has increased since the Bowers Report was published because, all prisoners who have been convicted since 2010, have been denied the right to vote in New Zealand's general elections.

But democracy gives "hope to human beings that their lives can be freed from the curse of violence and cruelty. Persuasion rather than force, compromise and reform rather than bloody revolution, free and open encounters rather than bullying and bossing, a hopeful,

experimental frame of mind …[it] breeds possibility: people's horizons of what is think-able and doable are stretched…" (Fetterman, 2010).

However, when the interests and/or voices of the marginalized are denied, or ignored by policy makers they are disempowered, their right to democratic participation is denied and the policy agendas are set by the powerful.

It is vital that prisoners who are significantly marginalised and disempowered are reconnected to society and being able to vote in general elections is one such essential step to take to begin this process.

5.3.2 The Need for the Hard of Hearing Advocacy to be Heard

When the writer was employed as the Executive Officer of the Health Consumer Alliance of South Australia she witnessed government funding of advocacy programmes in an attempt to ensure health consumers were able to speak out at power levels perceived to be comparable to those of health professionals working in the same sectors. In reality though, there are very complex issues underscoring the inability of consumers to gain a voice and operate at the same level of power in New Zealand as the Government regularly announces new policies that were developed without consultation.

At least the South Australian government attempted to give the consumer an equal voice. In comparison the voice and need to be heard by New Zealander's who are hard of hearing is unheard and actively denied. An example of this was the recent Tender released by Veterans Affairs (VA), calling for bids on the delivery of national audiology services where they had not consulted the consumer organisations or the New Zealand Audiological Society (NZAS). Fortunately, legal action from the NZAS and strong lobbying from consumers halted the Tender process. Bulk funding of audiology services will deny the needs of individual Veterans, because one size does not fit all when considering hearing aids.

5.3.3 A Prisoner has a Right to Access Justice

People who are hard of hearing rarely have any outward physical manifestation of being differently able, instead, choosing to use technology such as amplified hearing aids alone or in combination with loop system access or remote microphones and cochlear implants or bone anchored hearing aids. We read lips, eyes, facial muscle expressions and body language; we need captioning on television and movies and when all else fails we use the written word as our way of achieving effective communication.

When wanting to communicate and participate actively and knowingly in the world of the hearing-able, it really is vital, if the hard of hearing are to be heard, that friends and family make space and enable communications through captioning and New Zealand Sign Language. This is the equity, needed by people who are hard of hearing, to enable access in the world of the hearing able. But, sadly, as is often researched and reported, stigmatization and bearing the brunt of social derision is all too common for people who are hard of hearing.

5.3.4 Being Marginalised

From the evidence reported in this thesis it is reasonable to deduce that there is a significant prison population who are, in addition to being geographically and punitively isolated, are further marginalised by their inability to hear at the same level as their peers.

As the law and policy research and review section of this thesis proceeded, discussions were held with audiologists, Corrections staff and hearing therapists working with prisoners. From these discussions it became evident that the approach this research was applying in regards to identifying marginalization caused through hearing loss needed to be augmented with Government level advocacy in an effort to have policy developed that would address the judicial system marginalisation of prisoners with hearing loss.

The New Zealand Government has allowed the situation to evolve to such an extent that now New Zealand prisoners self-report at a 1:3 hearing loss rate of occurrence but the Department of Corrections has no formal method for occurrence identification, reporting or rehabilitating. In addition, the Foundation is now being asked to help in legal cases where people have either been denied justice or denied a voice in Court.

Recognising the severity of the situation, over an 18-month time period the writer was repeatedly frustrated and forced to consider and reflect upon possible creative solutions to the barriers presenting to this research proceeding. Eventually, by developing an overview of current national and international credible literature a Brief (Appendix A) was sent to three Ministers of the Crown in the New Zealand Government with portfolios that held hearing health and or prisoner care responsibilities.

After outlining the national and international academic research findings, the writer advised the three Ministers in writing of the need to identify prisoners with hearing loss when they joined the prison population. As these concerns were directly related to the “Vote Health” Government budget correspondence was sent by the writer to the Hon Tariana Turia,

Minister for Disabilities and Associate Minister for Health, which outlined the national and international research findings; requested the inclusion of a question into the Prisoner Health Survey and asked for a meeting.

Minister Turia advised that the correspondence about the issue raised should be referred to Dr. Pita Sharples, the Associate Minister for Corrections. Accordingly, correspondence was sent to him, outlining the national and international research findings; requesting the inclusion of a question into the Corrections Prisoner Health Survey and asking for a meeting. He responded by advising the matter should be raised with Hon Anne Tolley, Minister for Corrections.

Once again, the writer corresponded to yet another Minister, outlining the national and international research findings about prisoners with hearing loss; requesting the inclusion of a question into the Prisoner Health Survey and asking for a meeting.

This process of letter writing to Members of Parliament and response chasing by the writer took many months and considerable tolerance as each Minister's office either 'lost' or 'forgot' to redirect the correspondence which the writer needed to send three times! There were significant time delays in the ethnographer's correspondence being sent on from one Ministers office to the next and it had to be resent by email to the Minister for Corrections as the copy got 'lost' in transit between the Associate Minister for Corrections and Minister for Corrections office. It took many months to achieve a response from the Minister of Corrections as the correspondence was initially sent to the Minster for Disabilities who sent it through to the Associate Minister for Corrections who sent it through to the Minister for Corrections. The practice of referring an individual with an issue that is going to require a significant budget allocation from one Minister to another is a time-honoured tactic of delaying action with the hope that the supplicant will give up the appeal to the Ministers.

The focus of this research then shifted from analyzing and identifying whether hearing loss was a cause of marginalization, to ensuring the previously recognised marginalization that could be attributed to hearing loss, as identified by Bowers and self-identified by prisoners, was addressed operationally by the Department of Corrections.

When, in the ethnographer role the writer was meeting with Donaldson who advised that following receipt of her correspondence Minister Tolley met with both her and the CEO of Corrections. Apparently, one of the parties in the meeting complained to the Minister about the ethnographers' persistence and the Minister responded that the writer was 'being a

good advocate for her community'. Though these types of negative comments are frequently directed against trailblazers, the fact that this information was disclosed by Donaldson indicated a level of trust had been established between her and the ethnographer.

Minister Tolley then determined the issue of prisoner hearing screening was operational in nature and she directed that Donaldson, the Corrections Department Director for Offender Health, work with the writer to discuss the advocacy recommendations and implement change for this group of prisoners. After receiving the letter from the Minister of Corrections in late September 2012, the writer emailed Donaldson and met with her in a café in Wellington on October 24, 2012. The writer had gone a full circle, from meeting Donaldson prior to communicating with the Minister for Corrections and then being directed by the Minister to meet with Donaldson again!

This was a groundbreaking meeting in that, Donaldson advised, both the Minister and the CEO for Corrections supported the introduction of the Census question on hearing ability being inserted into the Prisoner Health Survey. It was being implemented into two prisons prior to Christmas 2012.But, there is no certainty that this has occurred as Donaldson reported shortly thereafter that they would be doing the inappropriate hearing screening at Springhill Prison and the indications are that the questions were not inserted into the MOI.

In consideration of the environment that ethnographic hearing advocates are working within, in the mid period of this thesis development public sympathy towards the sector moved from ambivalence and negativity to running at a high level in support of the Deaf community and the deaf/Hard of Hearing sector.

This is because the New Zealand Government's Speaker of the House initially failed to allocate funding for the provision of adequate captioning to enable access to the Parliamentary debates by the recently appointed Greens Party List (non-elected) Member of Parliament Mojo Mathers, who is profoundly deaf. Following significant outrage from many quarters, this decision was rescinded and it has resulted in an increased level of public awareness and sympathy for people who are Deaf and deaf/Hard of Hearing.

The National Foundation for the Deaf received some unsolicited public comment that Member of Parliament Ms. Mathers should provide her own supports to achieve equity with her hearing abled colleagues as she knew of her disability before she became a Member of Parliament. However, the feedback was overwhelmingly in favor of her

receiving full government support to gain equitable access to the Parliamentary debates and her work requirements.

Consideration is next given to identifying the early intervention and social support services available to incarcerated and non-incarcerated New Zealand citizens diagnosed with ear disease and hearing loss.

Prisoners are distributed nationwide, with the exception of the West Coast of the South Island, which is geographically inhospitable. When considering health service delivery it is necessary to consider where the service-demand is situated. This is because the health care needs of prisoners are the responsibility of the DHB in the region where the prison is located. The writer was advised by the Ministry of Health Disability Support Service that the DHB is required to fund the health care of all prisoners in their region, no matter where the prisoner's original point of origin at sentencing may have been, which is a heavy financial burden.

Also, on any given day 44,000 individuals are under Corrections' management and for every person serving a prison sentence in New Zealand there are approximately five serving a community sentence or order (Parliamentary Counsel Office, 2014b).

The results from the Prisoner Health Survey 2005 from the 423 New Zealand prisoners surveyed (317 males and 106 females of which 224 were Maori and 199 non-Maori) 1:3 prisoners self-reported some degree of difficulty in hearing in a group conversation even when wearing a hearing aid if they normally do so.

But, the results from the Department of Corrections Health Analyst review of their operational health database in May 2012, given to the writer by Faisander from Corrections, is that of the over 8,000 prisoners on the database on that particular day only 109 were reported and recorded on the health database by Prison Officers as having some form of hearing loss. The gap between prisoner self-reporting and official reporting is very significant as it shows that prison staff are unable to recognise when a prisoner has hearing loss as they only seem to recognise profound deafness.

Services available to the general population for the diagnosis of hearing loss and support services were analysed from the perspective of citizens aged 18 years and over, which, in New Zealand, is the pre-dominant age of when many adult health services commence, with the expectation that the service user has left high school.

Findings were that there is no formal service similar to the Newborn Hearing Screening Programme for the detection of hearing loss in those aged 18 years or over in New Zealand. It is generally by good luck or chance that a person is actually hearing screened, or by family members persisting in prompting them to be tested.

Hearing loss is still perceived by many as occurring mainly in the “over 60s” but the New Zealand Ministry of Health has not established a satisfactory screening programme for this age group either or assured them access through either of their funding programmes to low or no cost hearing aids.

The Department of Corrections does a considerable amount of intervention work with prisoners addressing presenting issues such as high addiction and low literacy rates. Prisoners often have comorbidities of health and significant social issues and now the ethnographer is advocating that prisoners need to be hearing screened to ensure this issue is also addressed. Stanley (2011, p.7) reports “[t]here have been improvements in the numbers of prisoners involved in employment activities, vocational training, and literacy or educational courses” which is pleasing. Hopefully, this will progress even more rapidly now that the next generation of potential prison inmates have been predicted by Government as the 17% of children who have a parent who is either a prison inmate or serving a community sentence.

These children need a wraparound social and welfare support service, which must include regular hearing screening tests and this recommendation will be included in the next advocacy pack sent by The National Foundation for the Deaf to every Member of Parliament.

Life Unlimited, Hearing Services provides a government funded hearing therapy service where 28 Hearing Therapists offer a cost-free national service for people who are New Zealand citizen and permanent residents aged 16 years and over who have hearing loss. A referral to this service is not required and Hearing Therapists visit Prisoners as requested by the Prison Health Service.

The twenty-eight hearing therapists are required to meet the needs of over 700,000 New Zealanders with hearing loss and though this is a well-respected service, it is under funded and there are impossible service delivery expectations.

In some respects the shortfall for support and information provision to adults with hearing loss is picked up by The National Foundation for the Deaf and the Hearing Association

which has 28 branches nationwide. Neither of these organisations receive government funding and, in 2012, the Foundation received in excess of 7,000 calls and emails of enquiry whilst having to fundraise to cover the cost of their advocacy and support services. The Foundation incurred a deficit of over $49,000 and the shortfall resulted in the disestablishment of two roles in their advocacy and support services to ensure 2013 was a surplus year financially.

By failing to fund sufficient support and advocacy community programmes for people who are hard of hearing, the New Zealand Government shows how little they understand or care about the reality of living with a significant communication disorder as hearing loss can be.

It also shows that the Government community funding contracting team does not understand the difference between therapy, as provided by the 28 hearing therapists and peer support as provided by people who “walk the talk”. Nor do they understand the need for complex advocacy and human rights cases in response to the all too frequent neglect of New Zealanders’ who have hearing loss.

This country has a hearing loss tragedy unfolding in silence and it is hoped by the writer that this research has raised sufficient noise on the reality of life for people with hearing loss in New Zealand for questions to be asked on how things can be done better.

CHAPTER SIX

BEING HEARD

6.1 Summing Up

This thesis endeavors to contribute to methodology by combining auto ethnography and Fetterman's ethnographic life-stages as a component of qualitative participatory action research. This included the researcher lived experiences of hearing loss, critical analysis of participatory research and disability theory too. An analysis on whether the policy recommendations from Bowers' research (1981) which would have addressed prisoner marginalisation caused by hearing loss was done to determine if they had been applied. The thesis does make a contribution to the literature through coining the concept 'autoenthnographic advocacy' and showing how learning from experience has helped to develop critical policy engagement. Autoenthnographic advocacy applied in the thesis in the shape of dialogue and correspondence was entered into with the State Corrections service on the need to introduce prisoner hearing screening.

Further discussions covering the areas of project design and delivery were held with the government contracted private prison service Serco and autoenthnographic advocacy was applied through correspondence and meetings with the various Ministers of the Crown holding the portfolio's responsible for disability services and inmate management (Corrections and Serco) was also done.

In addition, participatory research elements were offered, by the objective hearing screening done by trained hearing therapists from Life Unlimited Hearing Services who used standardized hearing testing equipment and by the self-selected group of 100 male prisoners recruited through self-selection from a representative population. Pure tone audiometry using standardized equipment and brief subjective hearing histories were recorded by hearing therapists who were not Corrections employees.

For the duration of this project there were crossing paths of objective and subjective participatory research which added in elements of theoretical complexity and active pragmatism which is described as "a reasonable and logical way of doing things or of thinking about problems that is based on dealing with specific situations instead of on ideas and theories" (Webster, 2015).

This thesis strives to contribute to the literature on governance in prisons by drawing attention to the need for a posteriori measures to ensure the health and rehabilitation potential of prisoners with hearing loss are recognised and realised, and the capacity of prison staff to understand the needs of these prisoners is enhanced.

Prison officers in New Zealand prisons are currently working in a situation where 1 in 3 prisoners have hearing loss. In some quarters, prisoners with disabilities are viewed as the most powerless, disadvantaged and vulnerable in society, yet they are reported as eliciting negative judgments such as shame and disgust from the more powerful. But, the powerful are those most able to initiate the change so desperately needed by prisoners to ensure a change in their life paths from recidivism to successful re-integration. Nussbaum's list of Central Human Capabilities outlined a set of opportunities or substantial freedoms that every person has the opportunity to exercise in action, which clearly defines what prisoners with hearing loss need to gain equality.

When considering the practical application of these capabilities to the needs of prisoners with hearing loss and to those of other marginalised people with disabilities too, they will give them the range of rights as defined and advocated for by the Convention on the Rights of Persons with Disabilities (CRPD) and the Universal Declaration of Human Rights 1948.

Also, by applying the Capabilities Approach through human rights as defined in the CRPD, governing bodies have the opportunity to increase the power of vulnerable prisoners, enabling their position in society to originate from the same level and thus the application of the equally balanced social contract becomes possible.

In the New Zealand prison population, prisoners will present with both unrecognised or non-rehabilitated pediatric or adult on-set hearing loss and both groups will need active hearing loss identification and support. This will enable them to successfully communicate and integrate firstly into the New Zealand prison population, then to participate in any hearing loss rehabilitation and recidivism prevention programmes while in prison and at release back into their community.

Research has shown that there was no Government policy response to recommendations from Bowers (1981) following her findings that 100% of Maori research subjects and 84% of European research subjects had abnormal ears and/or hearing or a history of ear disease. Although, these results were viewed as contentious at the time, they were

released. They clearly indicated there was a significant issue of previous or on-going ear disease and hearing loss in the New Zealand prison population.

Hearing loss was the most prevalent self-reported sensory disability in the 2005 New Zealand Prisoners Health Survey (the 2005 Survey). Though hearing screening was not done, the prison population self-reported that hearing loss occurred at the rate of 1 in 3 (over 33%). These findings are slightly lower but reasonably in line with U.S. research on prison populations where hearing loss occurrence after hearing screening was done has been reported at 36% to 48%.

It is also reported in the 2005 Survey that prisoner access to medical care is haphazard, which supports the notion that referrals to hearing loss rehabilitation services will be erratic too. Note that, ear disease or the history of it was not surveyed, meaning that a statistical comparison of Bowers' findings to the 2005 Prisoner Survey is not possible.

To conclude the summing up, it was evident that Bowers' recommendations to address the situation of prisoners with hearing loss were not implemented and that of the 100 prisoners who self-referred for testing in 2014, 52 required further assessment from audiological and clinical services.

Prisoners with hearing loss in New Zealand prisons remain marginalised because hearing loss is not routinely identified at admission; they are geographically and socially isolated as a result of incarceration and they are democratically marginalised because a 2010 amendment to the Electoral Act bars prisoners sentenced and incarcerated since 2010 from voting in the general elections. Of note, they are also institutionally marginalised by Corrections who have failed to respond to the need for hearing screening and rehabilitation of this at-risk group of inmates and furthermore prisoners are judicially marginalised due to the lack of captioning or New Zealand Sign Language interpreters being available.

6.2 Recommendations

Though the pool of prisoners tested was small at 100 and it was a self-selecting sample, the results indicate that the number of prisoners with hearing loss in New Zealand prisons has not decreased since 2005 and that there is a significant and serious need to implement a range of hearing loss recommendations across all Corrections and Serco facilities.

These include ensuring Serco and Corrections staff, who know how to communicate using New Zealand Sign Language are rostered to work with Deaf prisoners **who use** New Zealand Sign Language to communicate. When Serco management were queried as to why this practice was not already established they advised that the risk or threat of staff being groomed and emotionally captured by skillful prisoners was the reason why it had not been done. In fact, to overcome this risk Serco has the opportunity to implement affirmative action in their recruitment to ensure as many new recruits as possible are able to do New Zealand Sign Language and that current staff are required to learn basic sign language skills as a part of their on-going professional development.

There is also a need to ensure that prisoners who have hearing loss and **do not use** New Zealand Sign Language to communicate are able to understand the judicial process by providing professional captioning services for Court, Parole Board hearings, meetings with legal Counsel and all other meetings that will have significant impact on their lives.

Also, Serco, Corrections and the Ministry of Health Disability Support Services policy staff need to collaborate to develop a hearing loss rehabilitation fund that Corrections can use to purchase hearing screening and hearing rehabilitation services for prisoners. It is also very important to identify prisoners who have hearing loss by placing the following check list, as used in the 2014 research, in the Corrections Prisoner Health Questionnaire. Serco is already doing this.

Difficult Hearing Situations

- 1 on 1 in quiet: Y / N
- In groups/background noise: Y / N
- Difficulty using the telephone: Y / N
- Hearing the telephone ring: Y / N
- Hearing radio and TV: Y / N
- At home/socially/at work: Y / N

If there is a response of more than one ‘yes’, this indicates the need for further hearing and auditory processing testing.

The next area of concern to be addressed is to ensure Serco and Corrections staff understand how a person who has hearing loss will present and behave and where they

can go to gain assistance within the prison system. There is a real need to develop a DVD resource for Corrections and Serco front-line staff to see in their training forums, which will offer standardized information to all staff nationwide.

It is also recommended that two future research projects be implemented. The first one is to set up a cohort of MECF Hearing Loss Identification Project 2014 prisoner participants who require follow up and track their levels of recidivism after hearing rehabilitation intervention. This could best be achieved by the establishment of a Hard of Hearing Group or unit at MECF.

The second recommended research project is to carry out a hearing screening project of a cohort of 500 prisoners by independent hearing screeners using standardized and New Zealand Audiological Society (NZAS) approved hearing testing equipment. Discussions are now underway between Corrections and The University of Auckland in regards to the possibility of this research proceeding as definitive data is required to confirm the occurrence of hearing loss in New Zealand male and female prison populations.

6.3 Conclusion

This research has made a contribution to the literature on social policy by applying Nussbaum's capability approach to the life chances of prisoners in New Zealand as a basis for developing tests on hearing in prisons so as to develop more inclusive opportunities for some of the most marginalized New Zealanders.

The research comprises a unique participatory research collaboration across many parties including a lead researcher who has hearing loss; prisoners who did and did not have hearing loss; hearing health service manager and screeners; State and private senior prison management; University Professors from Universities in New Zealand and Australia and Members of the New Zealand Parliament.

Thus, this PhD research has made an original contribution to demonstrating the potential and pitfalls of working across sectors and working at multiple levels (locally, nationally and internationally) when addressing ways to improve the capabilities and associated life chances of prisoners. Some of the momentum was possible, as a result of working in local and international human rights arenas, which enabled the ethnographer to inform local practice to remind participants of the broader human rights context and also because of the knowledge gained from walking the disability discrimination path so wearily trodden by people with hearing loss.

This research design created space for all the parties that participated in this project who brought with them their diverse perceptions and agendas, which were worked through to achieve a policy outcome, which has taken steps towards achieving more social justice through participatory action research.

As described in chapter 3, the auto-ethnographer brings their personal values to the table when doing research and making policy suggestions and these values (in this case the capabilities approach) have a core bearing on the analysis from which the policy and governance recommendations will emerge.

This PAR research venture in New Zealand has contributed to making positive policy and governance changes for prisoners with hearing loss at Serco. This can be seen at the operational level by the inclusion of the questions, as outlined in chapter 4, Table 4.1, that enables a prisoner to inform on the extent of their hearing ability when completing their prisoner health questionnaire.

Though "policy disagreements are often multi-faceted and seemingly intractable [with] the underlying sources of disagreement… becom[ing] tangled and confused" (Robert & Zeckhauser, 2011, p. 1), this thesis has been able to clearly identify the difference between Corrections and Serco's policy responses to the issue of hearing loss in prisoners.

Through the process applied in this thesis the logical normative notion of policy analysis was established, from which the dispassionate policy statement emerges where the writer can state, based on empirical evidence, that hearing loss has been proven internationally to be a significant issue in prison populations.

The next step of the normative notion of policy analysis application is that the hearing screening and narrative questionnaire responses of 100 New Zealand prisoners indicate there is an issue of concern in New Zealand prison populations too.

When the questionnaire responses of both Corrections and the Ministry of Health are considered dispassionately, from the normative capabilities approach to policy, it is evident that both organisations do not have policies in place to manage and provide hearing loss identification, accommodation or rehabilitation.

The normative policy analysis underpins the development of a posteriori governance measures to test hearing and makes a case for a real and urgent need to transform policy

at both governance and operational levels in the Ministry of Health and Corrections and at the Corrections facilities too. However, as known from experience gained during this thesis development, Corrections has been unwilling to work collaboratively to do the research to identify the extent of the problem and have done instead hearing testing of prisoners using non-standardized equipment that has given unreliable results.

In policy terms, this thesis contributed by identifying and outlining the policy gaps currently evident at Corrections in regards to the needs of prisoners with hearing loss and it showed the different policy stances evident between Corrections and Serco. Serco was willing to learn and change their practices whereas Corrections is yet to develop recognition of the extent of the problem.

In governance terms this thesis contributed by identifying that prisoners with hearing loss in New Zealand prisons need to have policy developed that will incorporate their needs being met according to the Human Capabilities Approach as outlined in chapter 3, aiming to support their development to be what they are capable of doing and being. It also identified that the Convention on the Rights of Persons with Disabilities, as outlined in chapter 2, is an effective tool to use as a bridge to ensure the prisoners' rights are met to the level where the social contract can then become applicable to this group of disenfranchised citizens.

Progress is slowly being achieved, with the previous Minister for Corrections being supportive of extending this significant research being done in New Zealand. Also, discussion is underway in regards to the project being replicated in Australia with 100 woman prisoners. This thesis has raised the profile of prisoners with hearing loss at all levels and further auto-ethnography using these research findings will work towards the realization of the first step that prisoners with hearing loss need, which is to be offered the same opportunities to achieve at the same level as prisoners who do not have hearing loss.

Appendices

Appendix A: Correspondence to Minister and Deputy Minister for Corrections – template, also sent to Minister for Disability Issues

Hon. Anne Tolley
Minister of Corrections
Parliament Buildings
WELLINGTON

9 September 2012

Dear Minister

I have been working on a PhD which considers the situation of New Zealand prisoners who are hearing impaired and the public policy response to research done by Bowers (1981) where she reported 100% Maori and 84% European research subjects were found to have abnormal ears and/or hearing or a history of ear disease.

I wrote of my PhD findings to Minister Turiana Taria on July 21, 2012, with a request to meet with her and Minister Pita Sharples to discuss how hearing impaired prisoners fare. On following up with her office in early August they advised that Minister Turia requested I meet with MP Pita Sharples so I contacted his office to arrange a meeting.

Hon Pita Sharples office then advised I should meet with you and I contacted your office to arrange a meeting. I was then asked that I write again, hence this letter, outlining my findings as presumably the correspondence I was advised would be forwarded to you from Hon Pita Sharples has not arrived.

Hearing impairment is thought to occur at the rate of 1:6 in the general population (RNID 2011) whereas in the New Zealand prison population international and national (self-reporting) research indicates it occurs at the rate of 1:3. These findings are in line with US research on prison populations where hearing loss occurrence is reported as 36% to 48%.

In 2005 the New Zealand Prisoners Health Survey (2005)[10] reported 1:3 (over 33%) of prisoners self reported a hearing loss. Of the 1:3, **14.2**% of prisoners reported experiencing difficulty hearing someone in a quiet room; **24%** experienced difficulty hearing someone on the other side of a room

[10] Public Health Intelligence Occasional Bulletin No 37

and **31.2%** experienced difficulty when having a group conversation. Of note, this was the most highly self-reported sensory disability.

The New Zealand 2005 Prisoner Health Research (self reporting) also reports that prisoner access to medical care is haphazard, consequentially referral to hearing rehabilitation services will be ad-hoc and internationally it is reported that Corrections Staff are unlikely to understand how hearing impairment presents.

Of concern, a study done in British Columbia by Dahl in 1992-3, found that corrections staff there were five times more likely to perceive behaviours relating to inmate behavioural or personality problems as deviant than to perceive them as indicative of a hearing problem and 55% of the inmates with partial hearing loss expressed concern about being misjudged or mislabelled.

Add to this that in New Zealand Maori are significantly over represented in prison populations, with 50.8% prisoners being Maori, though they make up 14.6% of the general population.

Therefore, from this national and international research it is reasonable to believe that a significant number of Maori prisoners will have a hearing disability and their behaviours will be judged as deviant rather than a person attempting to overcome communication challenges in a volatile environment.

This is a serious issue and one that needs our urgent attention. I have been in discussion with the Department of Corrections, Flinders University and the University of Auckland about possible research requirements but it has become obvious during these discussions that there is sufficient evidence for immediate policy intervention to address the needs of prisoners with hearing impairment.

In an aside, please note though that there is a very real need for research to identify the specific types of hearing impairments most prevalent in our prison populations which may be informative on opportunities for earlier interventions in prisoner life pathways.
Having reviewed data nationally and internationally and discussing the situation in New Zealand with Corrections staff, I agree with the opinion of senior audiological staff at the University of Auckland that the New Zealand Prisoner Health Survey (2005) and international research findings give sufficient information to the Department of Corrections to know the occurrence rates of hearing impairment in prisoners will be very high.

Accordingly, there is a significant and serious need to:

- identify prisoners who are hearing impaired
- educate Corrections staff on how a person who is hearing impaired will present and behave
- train Corrections staff on what to do when they suspect a prisoner has a previously unrecognised hearing impairment
- appropriately support prisoners who are hearing impaired to ensure they are able to achieve gainful re-employment when they return to society

In line with this, it is recommended that the Department of Corrections adds a screening question in the prisoner health review screen which is done by the Prisoner's Case Manager on admission to prison after sentencing.

A question such as "*Do you have difficulty hearing in a group conversation with at least 3 other people in the group?*" could be added. When answered 'Yes', this indicates the need for further hearing and auditory processing testing. The specific question may need further discussion and trialling but the essence is that such a question needs to be asked.

We are aware that Corrections is receiving funding to support prisoner literacy development in the Budget which we applaud, but this may be premature as literacy development requires efficient auditory and or visual input or rehabilitative support as needed to achieve literacy.

I would very much appreciate the opportunity to discuss the needs of prisoners who are hearing impaired with you and ask that we meet?

Yours sincerely

Louise Carroll QSO, JP, GDPPA, MPM
CEO
The National Foundation for the Deaf

Appendix B: Official Information Act Response from the Ministry of Health

MINISTRY OF HEALTH
MANATŪ HAUORA

133 Molesworth Street
PO Box 5013
Wellington 6145
New Zealand
T +64 4 496 2000

Louise Carrol
National Foundation for the Deaf
Loiuse.Carroll@nfd.org.nz

Ref: H201403548

Dear Ms Carroll

Response to your request for official information

Thank you for your request of 12 September 2014 under the Official Information Act 1982 (the Act) for:

1. The baseline budget for the B4 schools service, and
2. The baseline budget for the cochlear implants service including a breakdown of this budget into child and adult cost allocations.

You indicated that baseline funding for the last full financial year for the programmes as defined above would be appreciated – if this is easily available. If not, for the previous year would be acceptable.

Thank you for agreeing to an extension to the timeframe and the information being provided to you by 12 October 2014.

The information relating to this request is itemised below.

1. The total B4 School Check budget for the delivery of the B4 School Check service in 2013/14 was $10,988,940
2. The annual baseline budget in 2013/14 for the cochlear implants service is set out below:

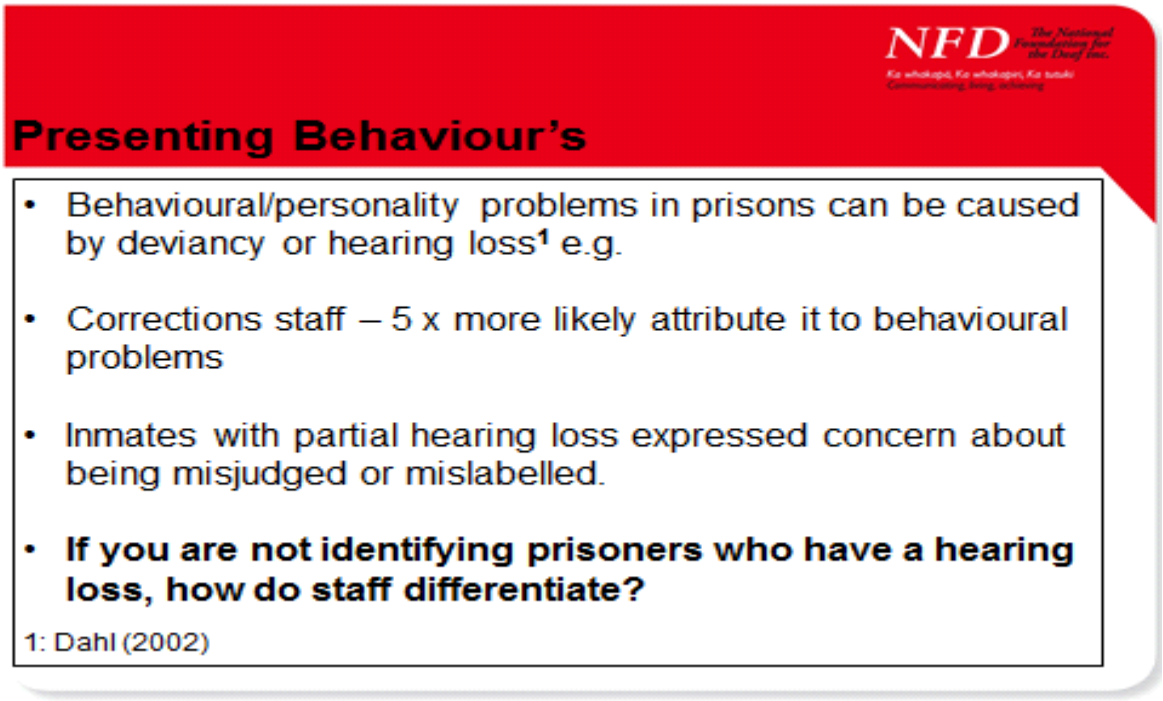
Cochlear implants- child	$1,268,744
Cochlear implants- adult	$1,811,360
Cochlear implants – child or adult (children get priority)	$1,900,000
Cochlear service funding - existing service users (child and adult)	$2,407,896
Total baseline	**$7,388,000**

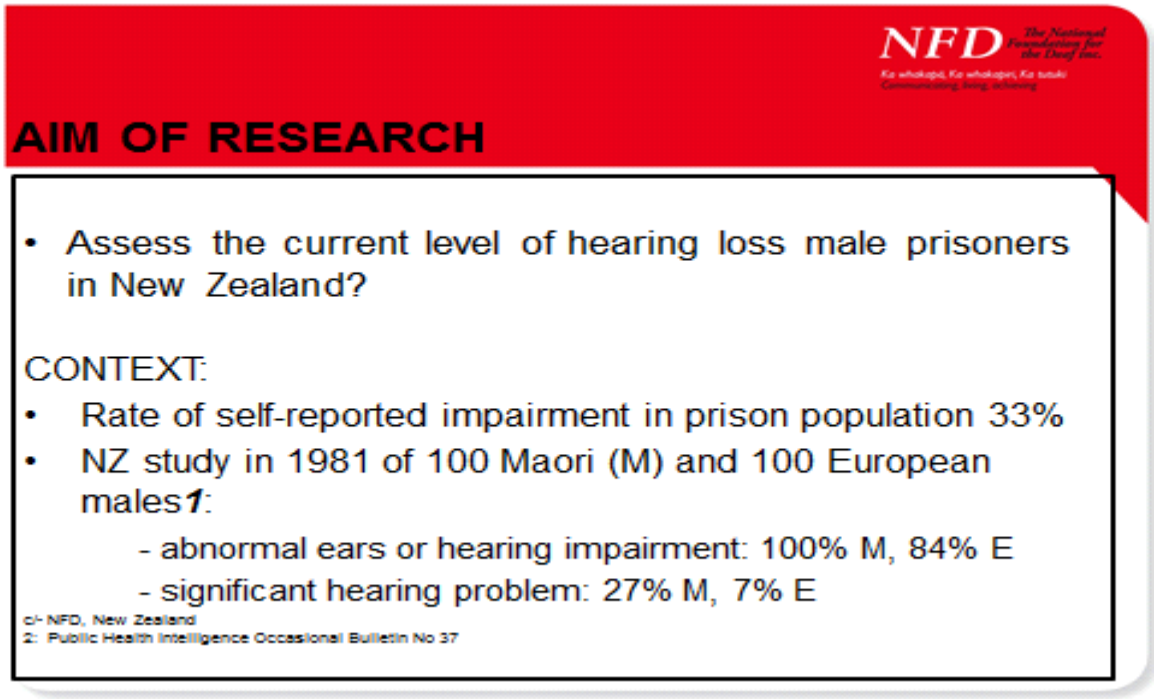
I trust this information fulfils your request.

Yours sincerely

Michael Hundleby
Acting National Director
National Health Board
Ministry of Health

Appendix C: Presentation of the Prisoner Hearing Loss Identification Project Outcome Presented to Mt Eden Correction Facility Management October 2014





Project Outline

Collaborators

- The National Foundation for the Deaf
- Life Unlimited Hearing
- Serco

} **Prisoner Hearing Loss Identification Project**

Study Design

Prisoner Hearing Loss Identification Project

- May to July 2014
- Enrolled 100 randomly selected male prisoners at Mount Eden Correction Facility, Serco, Auckland, New Zealand.
- Three hearing therapists employed by Life Unlimited Hearing carried out Pure Tone Audiometry and recorded a brief hearing history

Result Categories

The results of the hearing tests were categorised as follows:

No Further Action: the prisoner has no indication of hearing loss or obvious ear abnormality and does not require follow up

Monitoring: the prisoner has some indication of an evolving issue that needs monitoring but no active clinical intervention required at this stage

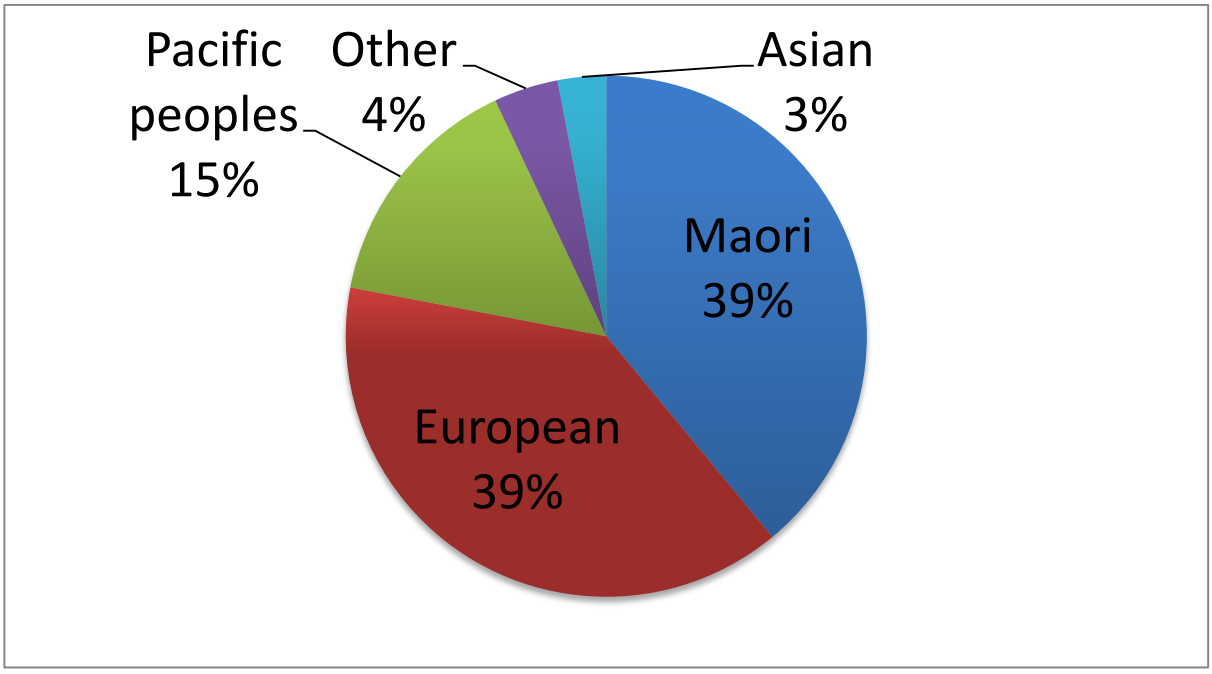
Audiological Referral: the prisoner has hearing loss or indication of some other audiological issue and requires full audiological assessment

GP Referral: the prisoner requires clinical care from a General Practitioner

ORL (ENT) Referral: the prisoner requires a GP referral to specialist level clinical care

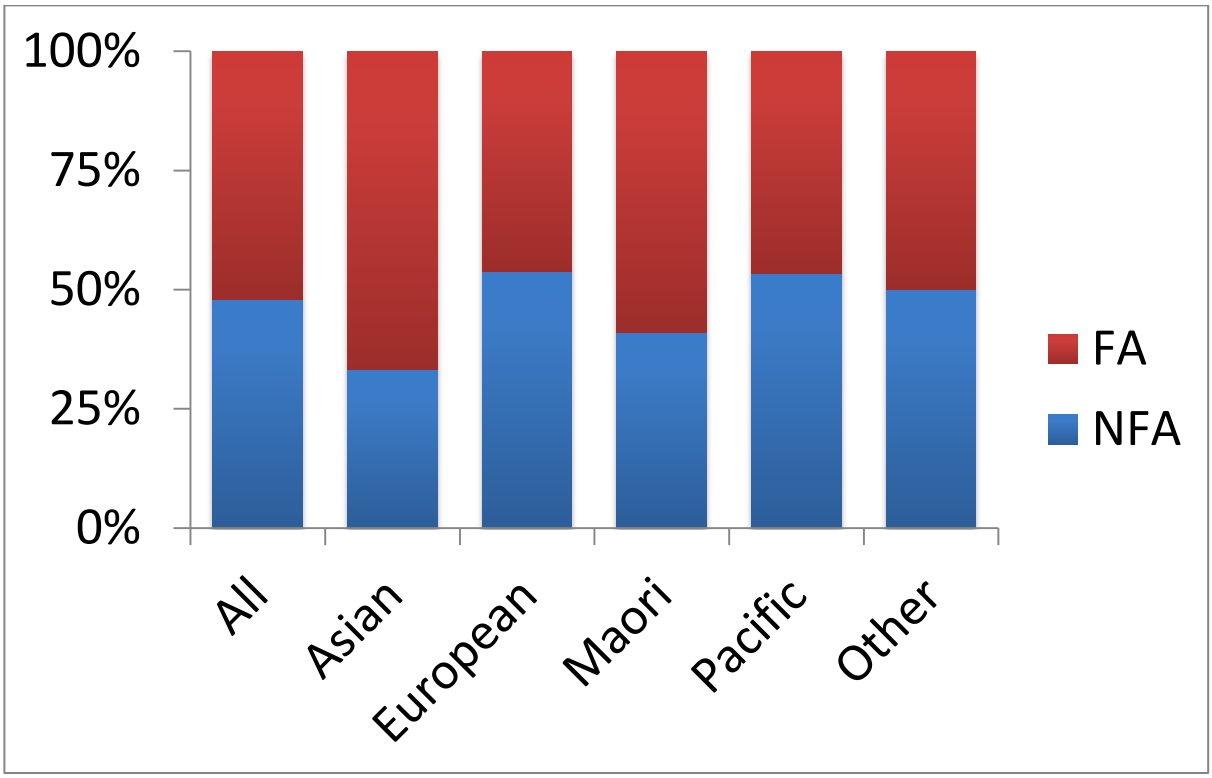
Participant Ethnicities

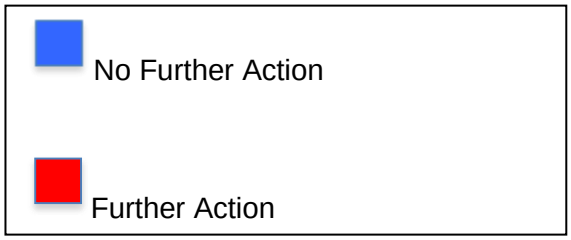
Mount Eden Corrections Facility Prisoner Hearing Loss Identification Project 2014



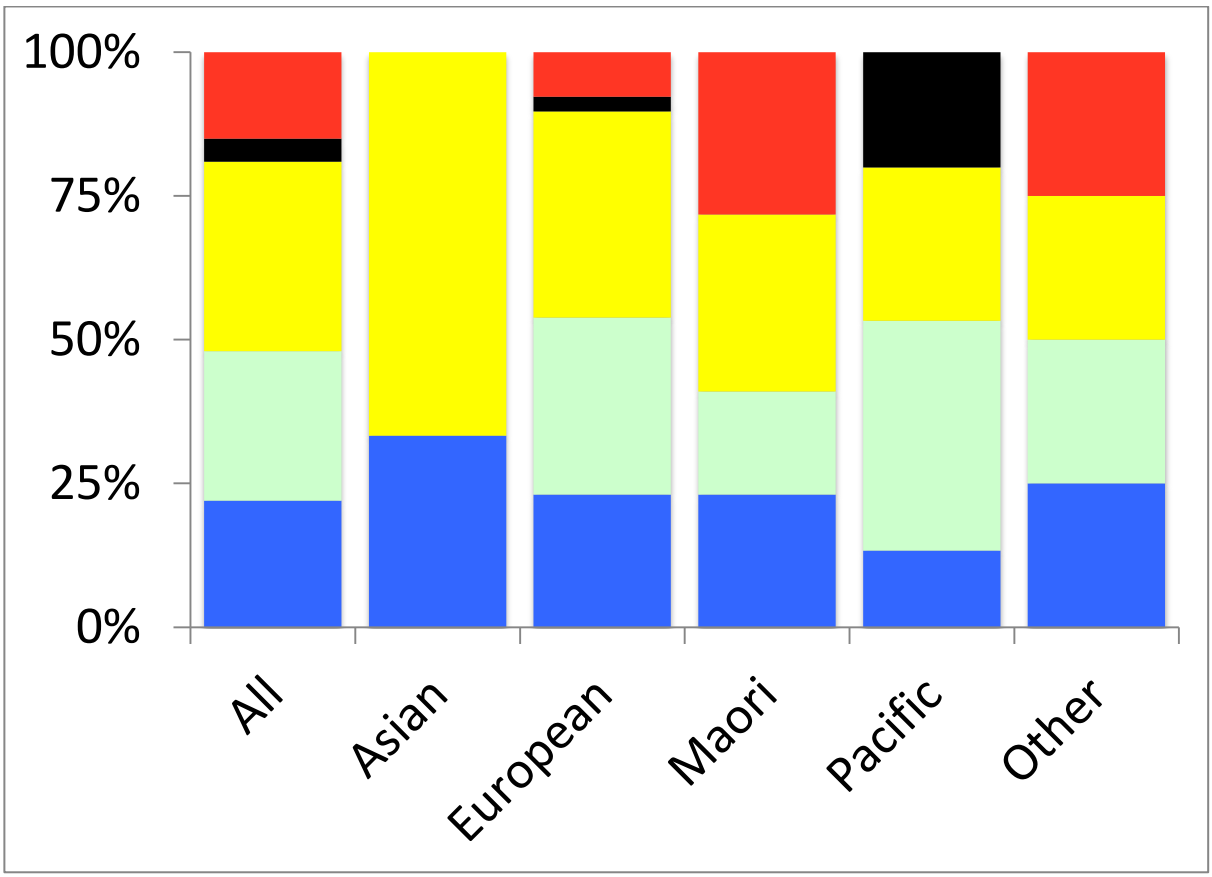
Prisoner Hearing Loss Identification Project MEFC 2014

Action and No Further Action Results



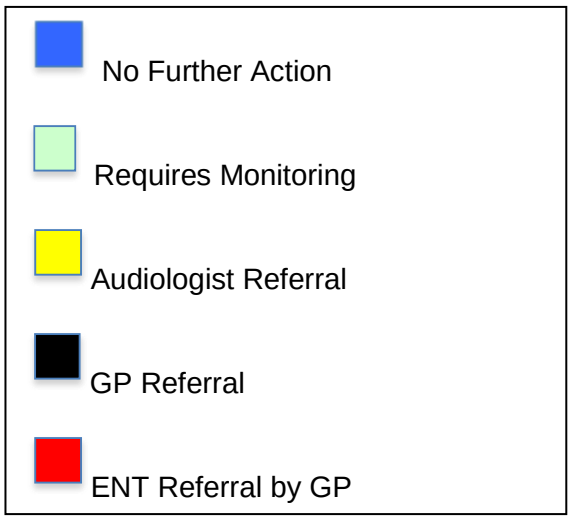


Recommended Actions: All Categories



November 2014

To ensure accuracy of results categorisation, prisoner categorisation high tone low tone hearing test results reviewed and allocations confirmed by Audiologist Mike Severn.



Where to from here?

1. The 52 prisoners identified as having hearing issues need to be followed up and referred to the appropriate service.

2. The following question to be included in the Prisoner Health Questionnaire
   Do you find it difficult to hear in any of the following situations:
   - 1 on 1 in quiet
   - in groups / background noise
   - telephone
   - telephone ring
   - radio and TV
   - at home/socially/at work

   If the prisoner responds 'yes' to any of the above questions we recommend they be given an initial hearing screening and needs assessment with a hearing therapist

3. Publish our collaboration and research findings in the Corrections Journal.

4. Establish Prison Officer bi-annual training session / workshop on interacting with prisoners who have hearing loss.

Thanks to...

Steve Hall, Director Reducing Re-offending, Serco Asia Pacific

Professor Janet McIntyre, Flinders University, South Australia

Gareth Sands, Prison Director, Serco MECF

Professor Peter Thorne, University of Auckland

Shelley Willett, Head of Clinical Services, Serco MECF

Follow Up
Louise Carroll: Mob phone: 021 07 66990
e-Mail: louise.carroll@nfd.org.nz

Appendix D: Flinders University Social and Behavioural Research Ethics Committee Provisional Approval

<Date>

Executive Officer
Social and Behavioural Research Ethics Committee
Research Services Office, Union Building, Flinders University
human.researchethics@flinders.edu.au

Dear Executive Officer,

Please find below my response to conditional approval for the above mentioned project, listed in the same order as on the conditional approval notice. Any additional or amended documents are attached.

Project No.:	**5114**	**Principal Researcher:**	**Louise Carroll**
Project Title:	Access and equity for marginalized groups		

No	Issues as outlined on the notice	Clarification
1	Reconsideration of the method used to contact and recruit ex-prisoners from NGOs. The Committee is concerned that ex-prisoners may feel pressured to participate if contacted directly by the researcher and suggests it would be preferable that no telephone contact is made and that documentation outlining the research be sent to ex-prisoners allowing them to contact the researcher if they wish to participate (item E5).	**Item E5 has been amended as follows:** **Group One: Ex-Prisoners** **Response** I will not contact the informants directly. They will be invited to participate by the Prisoners Aid Organisation or The National Foundation for the Deaf Inc. This will ensure that they do not feel pressured to respond to my requests. The informants will not be contacted directly. The third parties who assist me will ask the ex-prisoners if they wish to participate. They will also provide potential participants with the NFD 0800 toll free number. Once they have given their consent to participate I will interview them.

No	Issues as outlined on the notice	Clarification
2	Reconsideration of the response provided to item D7. The Committee suggests that permissions to conduct the research will need to be sought from all the groups listed in item D4 - NGOs, Managers of the Hearing Sector Advocates, the Government Department of Corrections and Ministry of Health. If yes, please provide copies of letters granting permission	D7. Indicate any **permissions** required from or involvement of other people (employers, school principals, teachers, parents, guardians, carers, etc) and attach letters or other relevant documentation as applicable. **Response** The research is being done independent of all organisations excepting for the National Foundation for the Deaf Inc who are providing the 0800 toll free number and study leave from my paid position as CEO, as required, to enable this research to proceed. As this is independent research, permission to conduct research is not required.
3	*Confirmation that data will be stored securely at Flinders University / Southern Area Health Service for a minimum period of 7-years given that item E7 states that data will be stored by the National Foundation for the Deaf for 7-years, as per New Zealand law (items E7 and E8).*	I will comply with the requirements of the committee and my data will be submitted to my supervisors for storage and potential review by examiners. At all times I will ensure that the data is kept confidential.
4	*Confirmation that no other Ethics Committee(s) need to provide ethics approval for the research to be conducted. The Committee suggests that ethics approval from New Zealand may be required. If yes, please outline from whom and provide a copy of the ethics approval letter on receipt (item F1).*	I can confirm that no other approval from a New Zealand Ethics Committee is required. Participants will be recruited through non-government organisations and Flinders University Social and Behavioural Research Ethics Committee Approval will cover.
5	Provision of the video/DVD that was listed as it was not included with the application (item G3).	No, there is no video/DVD listed on the Application to the Social and Behavioural Research Ethics Committee
6	Exclusion of the Letter of Introduction written by the student as only a letter written by the supervisor is required.	The Letter of Introduction has been excluded from the Application to the Social and Behavioural Research Ethics Committee

No	Issues as outlined on the notice	Clarification
7	Amendment of the Letter of Introduction written by the supervisor by: providing two separate letters, one tailored for the ex-prisoners and one for the other groups of participants; ensuring that it is clearly explained to both groups of participants that participation in the research will not provide any privileged access to healthcare/hearing services; ensuring that the time commitment expected of participants is clearly outlined in both letters as listed in item D9; ensuring contains the SBREC contact information footer which can be found in the Letter of Introduction pro forma available for download from http://www.flinders.edu.au/research/info-for-researchers/ethics/committees/social-and-behavioural-research-ethics-committee/applying-for-ethics-approval.cfm; and deleting the duplication of the supervisors contact details underneath the Flinders University logo.	Letters of Introduction to the two different groups have been provided by Supervisor, Assoc. Prof Janet McIntyre and are attached below. Both letters contain statements that: - participation in the research will not provide any privileged access to healthcare/hearing services - advise of the time commitment expected of participants - contain the SBREC contact information footer - the duplication of the supervisors contact details underneath the Flinders University logo has been removed.
8	(viii) Amendment of the Consent Form for Ex-Prisoners by ensuring that it is based on the pro forma available for download at http://www.flinders.edu.au/research/infofor-researchers/ethics/committees/social-and-behavioural-research-ethicscommittee/applying-for-ethics-approval.cfm.	Amendment of the Consent Form for Ex-Prisoners has been done, using the template available for download at http://www.flinders.edu.au/research/infofor-researchers/ethics/committees/social-and-behavioural-research-ethicscommittee/applying-for-ethics-approval.cfm.
9	(ix) Amendment of the Invitation to Participate Advertisements by ensuring that the Flinders University logo is placed in the header. A copy of the logo can be found in the Letter of Introduction pro forma available from: http://www.flinders.edu.au/research/info-for-researchers/ethics/committees/social-and-behavioural-research-ethics-committee/applying-for-ethicsapproval.cfm.	I have complied with this requirement and I attach the amended Invitation to Participate Advertisement for review by the committee

List of Attachments Please do not attach an amended copy of your application form.
Amended Item E5 - method used to contact and recruit ex-prisoners from NGOs.
Two separate Letters of Introduction, one tailored for the ex-prisoners and one for the other groups of participants.
Amended Consent Form
Invitation to Participate

Kind regards

Louise Carroll

To submit your response to conditional approval either:

Email to human.researchethics@flinders.edu.au, (Note: If email request, do not also send a hard-copy);

Mail to Executive Officer at: Flinders University, Research Services Office, Social and Behavioural Research Ethics Committee, GPO Box 2100, ADELAIDE, SA 5000

E5. If participants are required to complete a **questionnaire**, indicate the arrangements for ensuring the secure and confidential return of the questionnaire to the researcher (eg sealable, addressed envelope; personal collection by the researcher; other). Also indicate how participants will be informed of the arrangement (eg verbal instruction; written instruction in Letter of Introduction or at the end of the questionnaire; other). If information is to be provided via electronic or web-based technology, participants should be reminded in the written documentation and in on-line material that this is not a secure medium.

For all participants, if information is to be provided via electronic or web-based technology, participants will be reminded in the written documentation and in on-line material that this is not a secure medium.

If the questionnaire is sent by email, a read by recipient flag will be inserted on it. Stamped, return self-addressed envelopes will be included with each questionnaire posted out.

Group One: Ex Prisoners

When ex-prisoner participants contact the writer or the writer contacts ex-prisoners as referred to her by the NGOs, the ex-prisoners will be asked how they want their questionnaires provided: By post, email or Survey Monkey on the web.

Group Two: NGO's working in the Hearing Impaired Sector

If information is to be provided via electronic or web-based technology, participants will be reminded in the written documentation and in on-line material that this is not a secure medium.

Group Three: NGO's working with Ex-Prisoners

If information is to be provided via electronic or web-based technology, participants will be reminded in the written documentation and in on-line material that this is not a secure medium.

Group Four: Government - Department of Corrections & Ministry of Health

The Department of Corrections and Ministry of Health will be sent their respective questionnaires with a return self addressed envelope attached.

Appendix E: Template 1.1: Pro-forma Letter of Introduction to Ex-Prisoners

(Insert Date)

To whom it may concern

I am writing to you to request your co-operation in the doctoral research of Louise Carroll, Flinders Institute of Public Policy and Management.

We would be most grateful if you would spend about an hour of your valuable time answering a few questions on the following topic: Access and equity for marginalised groups: hearing loss

We have enclosed a copy of the interview framework including the questions so that you can decide whether you would like to participate. Your comments and ideas will be confidential and the research will comply with the Human Ethics Committee's requirements. This means that if at any stage you would like to withdraw from the study, we will honour your decision.

It is also important we let you know that even though we are very grateful for all of your assistance, we cannot provide any privileged access to healthcare or hearing services as a result of your support of this research.

Please do not hesitate to contact me at the email or phone address below if you have any further questions about this research. I will be happy to assist you. Assoc. Professor Mark Halsey would also be happy to answer any questions by email or phone or skype.

Yours faithfully

Dr Janet McIntyre
Associate Professor School of Politics and International Studies
Higher Degrees Co-ordinator for the School of Social and Policy Studies
janet.mcintyre@flinders.edu.au

Tel:+61 8 8201 2075

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 5114). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

Appendix F: Template 1.2 Pro-forma Letter of Introduction to Other Groups

(Insert Date)

To whom it may concern

I am writing to you to request your co-operation in the doctoral research of Louise Carroll, Flinders Institute of Public Policy and Management.

We would be most grateful if you would spend about an hour of your valuable time answering a few questions on the following topic: Access and equity for marginalised groups: hearing loss

We have enclosed a copy of the interview framework including the questions so that you can decide whether you would like to participate. Your comments and ideas will be confidential and the research will comply with the Human Ethics Committee's requirements. This means that if at any stage you would like to withdraw from the study, we will honour your decision.

It is also important we let you know that even though we are very grateful for all of your assistance, we cannot provide any privileged access to healthcare or hearing services as a result of your support of this research.

Please do not hesitate to contact me at the email or phone address below if you have any further questions about this research. I will be happy to assist you. Assoc. Professor Mark Halsey would also be happy to answer any questions by email or phone or skype.

Yours faithfully

Dr Janet McIntyre
Associate Professor School of Politics and International Studies
Higher Degrees Co-ordinator for the School of Social and Policy Studies
janet.mcintyre@flinders.edu.au

Tel:+61 8 8201 2075

This research project has been approved by the Flinders University Social and Behavioural Research Ethics Committee (Project Number 5114). For more information regarding ethical approval of the project the Executive Officer of the Committee can be contacted by telephone on 8201 3116, by fax on 8201 2035 or by email human.researchethics@flinders.edu.au.

Appendix G: Consent Form for Participation in Research

CONSENT FORM FOR PARTICIPATION IN RESEARCH

(by questionnaire)

I ….....

being over the age of 18 years hereby consent to participate as requested in the Letter of Introduction for the research project on access and equity for marginalized groups.

I agree that:

1. I have read the information provided.
2. Details of procedures and any risks have been explained to my satisfaction.
3. I am aware that I should retain a copy of the Information Sheet and Consent Form for future reference.
4. I understand that I may not directly benefit from taking part in this research and that participation in the research will not provide any privileged access to healthcare/hearing services.
5. I also understand that:
    - I am free to withdraw from the project at any time and am free to decline to answer particular questions.
    - While the information gained in this study will be published as explained, I will not be identified, and individual information will remain confidential.
    - Whether I participate or not, or withdraw after participating, will have no effect on any treatment or service that is being provided to me.
    - I may ask that the recording/observation be stopped at any time, and that I may withdraw at any time from the session or the research without disadvantage.

Participant's signature……Date……...

I certify that I have explained the study to the volunteer and consider that she/he understands what is involved and freely consents to participation.

Researcher's name…….....

Researcher's signature……..Date…….

NB: Two signed copies should be obtained. The copy retained by the researcher may then be used for authorisation of Items 8 and 9, as appropriate.

8. I, the participant whose signature appears below, have read a transcript of my participation and agree to its use by the researcher as explained.

Participant's signature……Date……...

9. I, the participant whose signature appears below, have read the researcher's report and agree to the publication of my information as reported.

Participant's signature……Date……...

Appendix H: Invitation to Participate

Invitation to Participate

To be distributed via websites; newsletters; bulletin boards and community radio

Did you know that in 1981 100 Maori and 100 European male prisoners had their hearing tested and their ear disease histories recorded and the results showed that 100% of the Maoris tested and 84% of the Europeans tested had abnormal ears and/or hearing.

In 1981 27% of the Maoris and 7% of the Europeans had an important hearing handicap and the researcher recommended that hearing rehabilitation be offered to prisoners.

If you are an ex-prisoner with hearing loss or ear disease please call The National Foundation for the Deaf (New Zealand) toll free on

0800 867 446

to complete a questionnaire on how your hearing loss has impacted on your life.

All information provided will be treated as confidential and your identity will be protected

Appendix I: Social and Behavioural Research Ethics Committee Final Approval Notice

Flinders University and Southern Area Health Service

SOCIAL AND BEHAVIOURAL RESEARCH ETHICS COMMITTEE
Research Services Office, Union Building, Flinders University
GPO Box 2100, ADELAIDE SA 5001
Phone: (08) 8201 3116
Email: human.researchethics@flinders.edu.au

FINAL APPROVAL NOTICE

Principal Researcher: Mrs Louise Carroll
Email: louise.carroll@nfd.org.nz
Address: NFD, PO Box 37729,
Project Title: Access and equity in marginalized groups
Project No.: **5114** Final Approval
Date: 23 May 2011 Approval
Expiry Date: **31 December 2014**

The above proposed project has been **approved** on the basis of the information contained in the application, its attachments and the information subsequently provided.

If you have any outstanding permission letters (item D8), that may have been previously requested, please ensure that they are forwarded to the Committee as soon as possible.

Additionally, for projects where approval has also been sought from another Human Research Ethics Committee (item G1), please be reminded that a copy of the ethics approval notice will need to be sent to the Committee on receipt.

In accordance with the undertaking you provided in your application for ethics approval for the project, please inform the Social and Behavioural Research Ethics Committee, giving reasons, if the research project is discontinued before the expected date of completion.

You are also required to report anything which might warrant review of ethical approval of the protocol. Such matters include:

- serious or unexpected adverse effects on participants;
- proposed changes in the protocol (modifications);
- any changes to the research team; and
- unforeseen events that might affect continued ethical acceptability of the project.

To modify/amend a previously approved project please either mail or email a completed copy of the Modification Request Form to the Executive Officer, which is available for download from http://www.flinders.edu.au/research/info-for-researchers/ethics/committees /social-and-behavioural-research-ethics-committee/notification-of-committee-decision.cfm.

Please ensure that any new or amended participant documents are attached to the modification request.

In order to comply with monitoring requirements of the *National Statement on Ethical Conduct in Human Research (March 2007)* an annual progress and/or final report must be submitted. A copy of the pro forma is available from http://www.flinders.edu.au/research/info-for-researchers/ethics/committees/social-behavioural.cfm.

Your first report is due on **23 May 2012** or on completion of the project, whichever is the earliest. *Please retain this notice for reference when completing annual progress or final reports.* If an extension of time is required, please email a request for an extension of time, to a date you specify, to human.researchethics@flinders.edu.au before the expiry date.

Fidelma Breen

For Andrea Mather (formerly Jacobs)

Executive Officer

Social and Behavioural Research Ethics Committee

23 May 2011

c.c A/Prof Janet McIntyre-Mills, janet.mcintyre@flinders.edu.au

Dr Mark Halsey, mark.halsey@flinders.edu.au

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