IN THE HIGH COURT OF NEW ZEALAND WELLINGTON REGISTRY

CIV-2015-485-235

UNDER

The Declaratory Judgments Act 1908 and

the New Zealand Bill Of Rights Act 1990

BETWEEN

LECRETIA SEALES

Plaintiff

AND

ATTORNEY-GENERAL

Defendant

affirmation 15e 8/5/15

JOINT AFFIDAVIT OF WENDI ALISON WICKS AND ROBYN MARY HUNT FILED ON BEHALF OF THE CARE ALLIANCE

8 May 2015

Next event date: For hearing 25 May 2015 Judicial officer: Justice Collins

> Counsel: Victoria Casey Tel: (04) 212 4679

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McLeod and Associates

Auckland

Contact Person: Richard McLeod Email: Richard@mcleadlaw.co.nz We, **Wendi Alison Wicks**, member and Convener of Not Dead Yet Aotearoa

("**NDYA**") and **Robyn Mary Hunt**, member of NDYA, both of

Wellington, solemnly affirm:

(A) Our Backgrounds and Experience

Wendi Wicks' Qualifications and Experience

- 1. Wendi is the co-manager of The Disability Clothesline and a registered celebrant. Her previous roles have included:
 - 1.1. Acting Chief Executive, Disabled Persons Assembly Incorporated
 - 1.2. National Policy Researcher, Disabled Persons Assembly Incorporated
 - 1.3. Policy Analyst, Central Regional Health Authority
 - 1.4. Equal Employment Opportunities Co-ordinator, State Services Commission
 - 1.5. Equal Employment Opportunities Co-ordinator, Ministry of Justice
 - 1.6. Community Worker, Christchurch
 - 1.7. Radiographer in Charge, Waimate Hospital
 - 1.8. Radiographer, Christchurch Hospital
- 2. Wendi was awarded a Masters in Social Work in 1998 by Massey University. Her other qualifications include Bachelor of Social Work with Honours (1989), Certificate in Community (1979) and a Diploma Society of Radiographers (London) (1972).
- 3. Wendi has been active in many community groups and official committees, including:
 - 3.1. Founding member, NDYA
 - 3.2. Member of the New Zealand delegation to the Ad Hoc Committee

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preparing the United Nations Convention on the Rights of Persons with Disabilities ("Disability Convention")

- 3.3. Chair and founding member of the Convention Coalition monitoring the Disability Convention as part of New Zealand's obligations under the Convention
- 3.4. Expert adviser to the government of the People's Republic of China on drafting anti-violence legislation
- 3.5. Chair and founding member of the Human Rights Network Trust
- 3.6. Member of the Human Rights Action Plan working party
- 3.7. Member of the Alternative Welfare Working Group
- 4. Wendi has been involved in many public campaigns, including:
 - 4.1. Accessible Buses Campaign
 - 4.2. New Zealand Disability Strategy
 - 4.3. Victoria University of Wellington Human Rights Complaint
 - 4.4. Accessible Public Transport Inquiry
 - 4.5. Campaign to Defend the Human Rights Act
- 5. Wendi has also made a number of international presentations on disability issues, including in:
 - 5.1. Beijing, 2014
 - 5.2. Copenhagen, 2011
 - 5.3. Cape Town, 2005
 - 5.4. Rio de Janeiro, 2000
- Wendi was recognised for her human rights work in 2000 through the Human Rights Commission Millennium Award.

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7. Wendi has multiple impairments as a consequence of a life-threatening brain tumour.

Robyn Hunt's Qualifications and Experience

- 8. Robyn is the founder and principal of AccEase, a company providing web and information accessibility and accessible communications services. She also co-manages The Disability Clothesline. Her previous roles have included:
 - 8.1. Human Rights Commissioner
 - 8.2. Policy Manager, Workbridge
 - 8.3. Equal Employment Opportunities Advisor, State Services
 Commission
 - 8.4. Consultant to the Royal Commission on Social Policy
 - 8.5. Journalist
- 9. Robyn was awarded a Bachelor of Arts in English Literature and Political Science from the University of Canterbury. She has also received an Honours degree in English Literature from Victoria University of Wellington, and she holds a Diploma in Public Sector Management.
- 10. Robyn has been active in many community and official groups, including:
 - 10.1. Founding member, NDYA
 - 10.2. Chair of the Board of Workbridge
 - 10.3. Co-President of Achieve, the National Post-compulsory Education Disability Network
 - 10.4. Co-Chair, Disability Strategy Sector Reference Group
 - 10.5. Member of the National Executive of Disabled Persons Assembly Incorporated

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- 10.6. Committee member, Wellington branch of Public Relations Institute of New Zealand
- 10.7. Trustee, New Frontiers Media Trust
- 10.8. Trustee, 2020 Communications Trust
- 10.9. Board member, New Zealand Guidelines Group
- 10.10.Peace Networker for the National Council of Churches
- 11. Robyn has published extensively and presented nationally and internationally on disability/equal opportunities issues, including:
 - 11.1. Keynote speaker at the 19th World Conference of Rehabilitation International in Rio de Janeiro, 2000
 - 11.2. 'Gender and Disability at Work', 1996
 - 11.3. 'Reframing the future. Disability and work in the New Zealand context', 1996, based on a Nuffield Scholarship to the UK in 1994
 - 11.4. 'Tu Tikanga Rights Now!', 1993
 - 11.5. 'Can a Disabled Person be the best person for the job? Disability and the merit principle in the Public Service', 1991
- 12. In 2001 Robyn was made an Officer of the New Zealand Order of Merit for her services to people with disabilities. She was made a Justice of the Peace in 1986.
- 13. Robyn has lived all her life with low vision. She is a member of the Blind Foundation.

(B) About Not Dead Yet Aotearoa

Our Position - Opposing Euthanasia and Physician Assisted Suicide

14. NDYA is a group led by disabled people. It is a voice for disabled peoples' opposition to euthanasia and physician assisted suicide.

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15. NDYA in opposing euthanasia and physician assisted suicide does not aim to be a mass membership organisation. We know that support for this group is akin to an iceberg, with more substantial agreement from disabled people being "below the waterline". Many who use support services have ongoing concerns that they do not say or do anything that might, in their opinion, put those arrangements at risk. Others feel their work, home or social situation could be compromised. However we are confident that the opposition to euthanasia and physician assisted suicide expressed by disabled Britons in the recent SCOPE survey (at "Exhibit 1") is a reflection of similar attitudes among disabled New Zealanders.

Our Grounding - A Human Rights Approach

- 16. NDYA's position on euthanasia and physician assisted suicide is strongly grounded in a human rights approach.
- 17. New Zealand has a strong record as a supporter of international human rights, as first articulated in the Universal Declaration of Human Rights in 1948. The framework for human rights has both generic rights and rights for particular groups. Within that later category is the Disability Convention, ratified by the New Zealand government in 2008. During the process of writing this convention New Zealand's leadership was widely acknowledged. Disabled people in New Zealand have, and continue to affirm its overarching place, and believe the place of the articles therein provide much value to domestic law.
- 18. NDYA agrees with and supports the Disability Convention. Given that both writers have been directly involved in UN negotiations that wrote this convention, and as members of the New Zealand government delegation, we are acutely aware of how strongly the Disability Convention is affirmed by disabled people. While the whole Convention upholds the human rights of disabled people, there are some particularly relevant parts:
 - 18.1. Article 10 of the Disability Convention affirms that persons with disabilities have a right to life, not death, which is to be effectively enjoyed by persons with disabilities on an equal basis with others.

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- 18.2. Further, in Article 4.3 of the Disability Convention there is a clear expectation that disabled people themselves shall be actively engaged in decision making processes concerning issues relating to them.
- 18.3. Article 33 describes a role for disabled people to be involved in monitoring a country's implementation of the Disability Convention in domestic law so that this can be reported to the relevant UN treaty monitoring body. In New Zealand the government by Gazette notice (at "Exhibit 2") has formally designated a body of organisations of disabled people (DPOs) as part of that monitoring mechanism.
- 19. NDYA's position is that in the light of the importance of the Disability Convention to disabled people, any legislation, policy or practice that can impact on disabled people must be examined in the light of its contents. As we have explained in more detail in this affidavit, NDYA believes that because of widespread, deficit-centred and inimical attitudes towards the value of disabled lives, any legalisation of euthanasia and physician assisted suicide would undermine and call into question our right to life, and our basic human rights. On these grounds, NDYA strongly opposes euthanasia and physician assisted suicide.

Our Standing - Support From Overseas Groups

- 20. NDYA is not a lone voice in its opposition. Groups that are similar to ours have expressed opposition to euthanasia and physician assisted suicide across the world. This can be seen, for example, in the U.S.A. amici briefs (at "Exhibit 3" and "Exhibit 4") filed by disability collectives in New Mexico and Florida. It can also be seen in evidence (at "Exhibit 5") that has been filed in British Columbia.
- 21. The validity of the concerns raised by groups like ours overseas in strong opposition to proposals to legalise euthanasia and physician assisted suicide has been acknowledged by government bodies that have reported on the issues. This can be seen for instance in paragraphs 276 and 280 of the recent 2015 Scottish Health and Sport Select Committee Stage 1 Report on the Assisted Suicide (Scotland) Bill (at "Exhibit 6").

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22. There is a very large body of materials that oppose the legalisation of euthanasia and physician assisted suicide from a standpoint of the rights of disabled people. In the very short time we have had to prepare this affidavit, under urgency, we have been able to refer to only a few of the many documents that are relevant to the issues presented by euthanasia and physician assisted suicide. With more time, we could have added many more references, including to peer reviewed journal articles. The evidence we have given below should be read in light of this.

(C) The Devalued Place of Disabled People in Society

- 23. To understand NDYA's opposition to euthanasia and physician assisted suicide it is important to know the position that disabled people occupy in society. At 24% of the population (according to Statistics New Zealand, at "Exhibit 7") disabled people represent a large segment of the New Zealand population who are at risk from changes to the law. We are the country's largest minority.
- 24. In the following section, we outline current societal prejudice. After doing that, we discuss the impact that the interaction between allowing change to the law on euthanasia and physician assisted suicide and these negative attitudes will have for disabled people.

Occupying a Marginalised and Disadvantaged Place

- 25. It is internationally recognised that disabled people occupy a marginalised and disadvantaged place in society because there are myths and stereotypes about who and how we are. Such myths usually centre on what it is believed that we cannot do, or how our lives are perceived. Among such negative stereotypes are:
 - Our lives are inherently unbearable
 - We suffer because of our state of being
 - Our lives involve an ongoing struggle against adversity, making us brave and inspirational

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- We have many deficits that make us unable to do things and participate in society
- We constantly need to be cared for, and that is costly and a burden
- We take resources, and don't contribute to society
- 26. The language and concepts are negative too:
 - Burden
 - Wheelchair bound
 - Unable to...
 - Suffering
 - Dependency
 - Special/special needs
 - Cost too much
 - Lesser state
 - A loss of dignity and independence
- 27. Such widespread assumptions, as reflected in the language we use, are also reflected in laws, policies, programmes and practices designed and delivered by those who are not aware of how best to design and deliver inclusively.

The Societal Consequences - Key Social Indicators

28. When non-inclusion or discrimination happens, disabled people frequently face multiple disadvantages. Their marginalised situation can be seen in the fact that disabled people face limited educational and employment opportunities, poverty and limited economic independence. The following

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scenario illustrates:1

A young man with a learning disability has always lived at home with a loving family, who nonetheless struggle with access to the education system and their local school. Because local schools are unwelcoming and there is bullying he is sent to a "special" unit. When he emerges at 21 years he has no qualifications and there is no day activity centre close by. The family struggles financially, and is not well connected to services and other families in a similar situation. The young man would like a job, and to live in a flat with others as other young people do.

- 29. Many disabled people must exist on benefits or if they are in employment most are in low paying jobs with limited prospects of career progression. Probably not many New Zealanders know this but it is lawful for disabled people to be paid well below the minimum wage, despite the 2007 repeal of the Disabled Persons Employment Promotion Act (which allowed for 'sheltered workshops'), if an exemption permit has been issued. A recent NZ Human Rights Blog article (at "Exhibit 8") shows that there were 897 exemption permits in force as at 11 February 2014, of which 660 allowed pay rates of less than \$5 per hour.
- 30. There is also a limited and diminishing level of home ownership, as one study (at "Exhibit 9") shows. Others (at "Exhibit 10" and "Exhibit 11") show that the costs of disability are significantly higher and that the combination of extra costs and low fixed income exacerbates the poverty in which many disabled people live.
- 31. Caregiver support, home help or any other kind of (community) support services may be required, but are not readily or adequately available. Studies also show (at "Exhibit 12") that the workforce providing these services are casualised, poorly paid and have limited training or a limited career progression structure. In such a setup of service provision, the choices service users can exercise are extremely limited, particularly for the 53% of disabled people that recent statistics (at "Exhibit 6") say have more than one type of impairment.
- 32. Disabled people also experience problems in access to health services. To illustrate:

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This story, and other scenarios we have referred to in this affidavit, are composites. They derive from the many many disabled people whose stories we know.

A young woman with high support needs and having more than one impairment lives in a rest home because there is no accommodation available in her area. Poor quality care and lack of personal and family support results in frequent urinary infections, and lack of support means she can only go out when a carer can go with her. She has no friends her own age to socialise with.

33. Additionally, there is a significant level of unmet health need and disabled people may have health issues ascribed to their disability, and receive inadequate health services as a consequence. For example:

A disabled man with visible physical impairment has a major stroke. His symptoms are ignored because of the presence of the impairments, almost causing his death. He has to fight to access recovery services, since there are assumptions that as a disabled person he will not need them.

- 34. The tragic case of "Ms A", which has been addressed by the Health and Disability Commissioner (at "Exhibit 13"), also illustrates problems in the healthcare system.
- 35. Associated with what we have described above, research studies indicate that medical professionals, including physicians, consistently and dramatically underestimate quality of life for their disabled patients, as compared to the assessments that the disabled individuals themselves make of their own lives. Research by Carol Gill (at "Exhibit 14") summarises some of the relevant literature that supports this troubling aspect of the healthcare system.

Other Consequences - Invisibility, Abuse and Violence

- 36. Disabled people additionally experience abuse and violence at significantly higher rates than for the general population. There is a limited body of New Zealand research (at "Exhibit 15") to provide local data, but international literature, most notably from Australia,² gives a high rate, around 3 times as high as for non-disabled people.
- 37. People in institutional settings are particularly vulnerable to abuse and violence from paid caregivers, but there is also an ongoing trail of abuse or killing caused by family/whanau. This can be seen in our table (at "Exhibit

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Λ comprehensive review of international research is found in Forgotten Sisters (2007), which is one section of the Resource Manual on Violence Against Women with Disabilities produced by Women With Disabilities Australia (www.wwda.org.au). The website contains a comprehensive collection of other abuse and violence data.

- 16") listing disabled people identifiable in newspapers as having been murdered in New Zealand.
- 38. Killings of disabled people also seem to attract a lesser sentence, as they are explained in terms of the disabled person's putative suffering or that they were better off dead (as in "Baby C", discussed in "Exhibit 17"), or that their lives caused their parent such ongoing and unendurable suffering that they were provoked into killing (as in Casey Albury Thompson, discussed in "Exhibit 18").
- 39. The abuse and violence and killing of disabled people is a further illustration of a dysfunctional social climate in which disabled lives are, contrary to the provisions of the Disability Convention, minimised, marginalised and seen as expendable.
- 40. Further illustrations of abusive practices that deny disabled people autonomy and bodily integrity are non-consented sterilisations (often described in terms of "menstrual management") and the female genital mutilation that has also been described (at "Exhibit 19") as the "Ashley treatment".
- 41. The "Ashley Treatment" is the removal of all female organs to obliterate the primary and secondary sexual characteristics, i.e. it results in a girl never physically maturing into a woman. This 'treatment' has been recently performed in New Zealand, despite the fact that Female Genital Mutilation is unlawful. In our view, this underscores the existing frailty of the medical system for disabled people.

(D) Government Recognition of Ongoing Problems

- 42. The problems for disabled people that we have noted above are recognised by the government to exist in New Zealand. That can be seen in the initial report that was submitted by the government to the Committee on the Rights of Persons with Disabilities (at "Exhibit 20"). It includes:³
 - ... 6. Disabled people are still disadvantaged: While there have been,

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³ Internal citations omitted.

and continue to be, improvements, many disabled people experience poorer outcomes in health, education, employment and elsewhere. The degree of relative disadvantage is still greater for women and for Maori and Pacific people.

- 7. Disabled people still experience social discrimination and practical barriers: While the Government has taken many steps to strengthen the standing of disabled people, constraints remain in the attitudes of some people, who see disabled people as less than equal. There are also physical and environmental barriers: for example, New Zealand's small population and geographic diversity means that some services are concentrated in main centres and are not readily accessible in more remote areas. ...
- ... 33. Despite legislation, disabled people still feel discriminated against. A 2008 survey indicated that 57 per cent of respondents identified disabled people as being subject to some or a great deal of discrimination. Approximately one-third of complaints to the Human Rights Commission involve allegations of disability discrimination, although a substantial majority of these are resolved or withdrawn.
- 34. Feedback suggests that disabled people may be perceived as having a lower quality of life as a result of their impairment and that this perception may influence decisions on medical treatment. ...
- 43. The last paragraph in the quote above has obvious relevance to this case. In our experience this is correct: disabled people are often seen as having a lower quality of life as a result of our impairment, and this perception can influence decisions by medical professionals.

(E) Concerns if Physician Assisted Suicide is Made Lawful

44. In a social environment where there are negative and discriminatory attitudes and behaviours towards disabled people as a group, NDYA believes that any changes to the law that would facilitate/allow euthanasia and physician assisted suicide would undermine the rights of disabled people as a whole and put them much more at risk.

Further Devaluation of the Lives of Disabled People

45. As we have explained above, society already devalues our lives as disabled people. That is based on the misperception that a disabled person, particularly someone with a severe disability, could not be a happy and contributing member of society. NDYA considers Jane (now Baroness) Campbell's evidence to the House of Lords Select Committee in 2004 (at "Exhibit 21", p235) on what may underpin this, to be insightful and useful:

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...society's view of terminal illness and [of] disability I think can be summed up in one word. That word is fear: fear of loss of opportunity; fear of denial of self-determination; fear of loss of control; fear of pain; fear of hardship; fear of being a burden to others. Many members of the public employed in the medical profession share these fears.

- 46. The legalisation of euthanasia and physician assisted suicide would only serve to promote the misperceptions based in these fears, as inherent in euthanasia and physician assisted suicide is the recognition that some lives are worth living to their end, while others are not; that some people would be better off dead.
- 47. Terminal illness and physical disability are not, of course, the same thing many people with disability are not terminally ill. But as Lives Worth Living Convener Craig Wallace explained to an Australian Senate Inquiry in October 2014 (at "Exhibit 22"), and which is also demonstrated in a report on the contribution of disabled people to society (at "Exhibit 23"), terminal illness can often bring with it disabilities which characterise the situation of disabled people who are happy and contributing members of society such as incontinence or requiring assistance in dressing, bathing, eating, toileting or in other activities of daily living.
- 48. Society will endorse the idea, through the legalisation of euthanasia and physician assisted suicide, that any lives having those characteristics are worse than death and not worth living. For those lives society would be saying that death is preferable to life, and that doctors are to be empowered to help a person to terminate their life. In that way society would be asserting that it is irrational for a non-disabled person to end his or her life, but rational for a disabled person to do so, and in doing this the law necessarily would be assuming, contrary to the Disability Convention, that disability is something to be avoided and that the world would be a better place if disability could be eliminated.
- That is highly problematic for disabled people, and stands to undo much of the progress the disabled community has made through the Disability Convention and other initiatives to address the marginalised and disadvantaged place we occupy in society.
- 50. It may also affect the support offered to the families of disabled people, to

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everyone's significant detriment. As Carol Gill explains (at "Exhibit 24", p34):

Most disability rights advocates who oppose legalized assisted suicide are not afraid that our families are out to get us. We are afraid that a society that refuses to expect and to provide for incurable conditions will abandon us and our families after we are no longer of apparent value to society. That prediction is not a paranoid fantasy or a groundless anxiety. The social and economic pressure to institutionalize incurably ill and disabled individuals plays out across the country everyday, often leading to premature deaths from complications of institutional treatment. Insidiously, there are no laws explicitly requiring nursing home placement; the system is simply set up to push people there by default. In this context, if assisted suicide gains wider legal reach, it will have a deadly double effect. It will not only advance the idea in our culture that it is reasonable for certain people to be helped to a hastened death, but it will also offer an alternative destination, assisted suicide, for socially abandoned individuals floating down the river towards the nursing home. The former effect is potentially more deadly than the latter. Expanding our comfort with letting go of 'suffering' people will ultimately lead to less support for our lives - whether it involves an antibiotic that is withheld, a ventilator that is withdrawn, or a message about being a burden that takes away one's will to live. ...

- 51. Disabled people have heard before about our lives being of lesser value and how that has been apparently sanctioned by actions of state and/or courts.
- 52. During the Third Reich the Nazi doctors had a 'practice run' on killing large numbers of people by starving, gassing and injecting them. The U.S. Holocaust Memorial Museum website records (at "Exhibit 25") that 200,000 disabled people were killed with legal permission under a "T4" programme targeting them for that treatment.
- 53. Similarly, eugenics was promoted as rational, scientific, progressive and humane, and was politically and socially respectable in many countries up to the 1930s. In New Zealand, for example, the Eugenics Education Society (founded in 1910) included prominent New Zealanders from many areas, including (at "Exhibit 26") the Prime Minister Bill Massey, the Chief Justice Sir Robert Stout, an Inspector-General of Schools, and an Inspector-General of Mental Hospitals. Woman too supported the Eugenics Education Society, with Dr Emily Siedeberg, New Zealand's first woman medicine graduate, being a prominent supporter.
- 54. Eugenics has since been repudiated, and rightly so. But not without significant harm being done by it to disabled people. On 2 December 2002 Oregon Governor John Kitzhaber issued a public apology (at "Exhibit

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27") to the 2,648 people who were compulsorily sterilized under the state's eugenics laws between 1917 and 1983. The Governor recognised in that apology that the majority of affected Oregonians "suffered from mental disorders and disabilities".

- 55. Also notable is the situation of Carrie Buck, the first woman compulsorily sterilised under Virginia's 1924 law to "prevent the procreation of persons socially inadequate from defective inheritance". That law was based on a 1922 "model law" written by Henry Laughlin, the head of the self-appointed Eugenics Records Office. In 1936 the University of Heidelberg awarded Mr Laughlin an honorary doctorate in recognition of his influence in establishing the compulsory sterilisation laws of the Third Reich.
- 56. After it came into effect the Virginia law was challenged in the U.S. Supreme Court. It upheld the law in 1927, with Justice Oliver Wendell Holmes writing:

We have seen more than once that the public welfare may call upon the best citizens for their lives. It would be strange if it could not call upon those who already sap the strength of the state for these lesser sacrifices. . . . It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes. Three generations of imbeciles are enough.

57. Research (at "Exhibit 28") now shows that Miss Buck was not an "imbecile" (whatever that means), and nor was her mother or daughter (the "three generations"). In fact, Miss Buck was raped and made pregnant by a relative of her foster family as a teenager, and then institutionalised to hide the shame.

Introduction of Contradictions in the Approach to Suicide

- 58. NDYA's second concern with euthanasia and physician assisted suicide relates to how that sits alongside suicide prevention in New Zealand.
- 59. Suicide is usually seen to be an impulse where some disorder of thoughts and emotions exist, and which should be assisted. But when it comes to choosing to end life, the legalisation of euthanasia and physician assisted suicide will send a message that the situation is to be reversed. Philippa

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Willets (at "Exhibit 29") encapsulates this as follows:

This huge contradiction says a lot about the value we place on disabled people's lives. "We must stop people committing suicide! Oh wait, they're disabled and want to commit suicide? Sure, hand them the pills."

60. Diane Coleman (at "Exhibit 30") has made a similar point:

For individuals who internalize the social oppression that declares severe disability to be undignified, the legalization of assisted suicide may convey the message that suicide is the best way to reclaim their dignity. It may even convey the message that suicide is the most honourable way to make one last contribution to a society that increasingly operates from a 'lifeboat' mentality, a mentality that tells the disenfranchised and despised to get out of the way, without ever seriously considering the decisions and motives of the policy-makers who shape the culture we live in.

61. Considerable effort is put in by any number of bodies, government and non-government, particularly for youth suicide. There are strategies and programmes to assist. NDYA affirms the value of suicide prevention programmes. It is concerned that those programmes will be contradicted and undermined by the legalisation of euthanasia and physician assisted suicide, and that this will create a discriminatory double standard for who is the focus of suicide *prevention* and who has access to suicide *assistance*. This is encapsulated in the cartoon below:



- 62. If society says through the legalisation of euthanasia and physician assisted suicide that life with a severe disability is not worth living, there is also the real risk that the 'right to die' is seen for disabled people to be a 'duty to die' pressuring us to 'choose' suicide over living a full life with a disability.
- 63. Finally on this issue we draw attention to what Stephen Mendelson (at

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"Exhibit 31") has called the "suicide contagion" that has been associated with the legalisation of euthanasia and physician assisted suicide in Oregon:

Another problem in Oregon is suicide contagion. According to the Centers for Disease Control, Oregon's already high suicide rate has increased much more than the national average; from 1999 (shortly after the Oregon Death with Dignity Act took effect) until 2010, the rate of increase for people age 35-64 was 49% in Oregon versus 28% nationally. Given the motto of Compassion & Choices and other "right-to-die" organizations is "My Life. My Death. My Choice." this should come as no surprise.

Mercilessly bullied autistic and LGBT youth can pick up this message that "my death" is "my choice"—a message which Compassion & Choices has displayed in the Capitol concourse for two weeks—and act on it. Those of us on the autism spectrum can take messages like this quite literally. Nikki Bacharach, the autistic daughter of Burt Bacharach and Angie Dickinson, committed suicide eight years ago. Her parents issued the following statement, according to Lisa Jo Rudy of About.com: "She quietly and peacefully committed suicide to escape the ravages to her brain brought on by Asperger's." This strange and creepy announcement is the logical product of Compassion & Choices' assisted suicide advocacy, where "peaceful suicide" is glorified and disability is viewed as "ravaging" our minds and bodies. This is disability discrimination and is unacceptable.

Dangers to Disabled People From Unquestioning Medical Professionals

- 64. Added to the concerns just noted, is NDYA's fear that the devaluation of the lives of disabled people that is assumed by euthanasia and physician assisted suicide will be internalised by disabled people, making them particularly vulnerable to pressure to commit euthanasia and physician assisted suicide.
- 65. While there may be put in place an 'independent' check in the form of medical professionals, their effectiveness in practice will be undermined by the negative societal views of disability, which will be further reinforced through the legislation of euthanasia and physician assisted suicide.
- 66. NDYA's fear is that this will lead medical professionals too willingly to assume that a desire for death in people with disabilities is a rational desire that should not be questioned. That is a risk whose realisation is made more likely by the research we have referred to above, which indicates that medical professionals consistently and dramatically underestimate quality of life for their disabled patients as compared to the assessments the patients make of their own lives.
- 67. These risks are expanded upon by Carol Gill (at "Exhibit 23", pp33-34):

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People with disabilities have more experience with physicians than most people. We know that medical mismanagement takes many forms and rarely is it flagrant or even deliberately malicious. Nonetheless, many of us have been harmed significantly by medical professionals who know little about our lives, who thought incurable functional impairments were the worst things that could happen to a person, and who were confident they knew best. Research has shown for some time that many health professionals believe life with extensive disabilities is not worth living; however, malpractice sanctions have prevented most from acting on those misconceptions. Whatever a particular doctor may have thought about the quality of our lives, she/he has known that the court could punish any physician who provided less support for our lives than for anyone else's life.

... When countless people with disabilities die every day from treatment withdrawal, in a legal procedure that is now so routine that it rarely reaches a court, when our lives are weighed in terms of the resources we consume, and when the law protects our right to refuse life-sustaining treatment but not our parallel right to request it, it is reasonable to believe that these things will get worse when doctors are given more licence to judge the hopelessness of incurable conditions and more impunity to act on their judgments.

As Carol Gill goes on to explain (at "Exhibit 23", p34), these fears are based not on a world full of cold-blooded doctors looking to take disabled lives, but on our real world; a world that contains health professionals who society tells to devalue the lives of disabled people and who often know very little about living a meaningful life with incurable impairments:

I am personally acquainted with many persons with disabilities who oppose assisted suicide, yet I do not hear any of us voicing fears about cold-blooded doctors out to get us. We are, in fact, much more frightened by the doctors who are out to help us but who see our lives as burdensome and who know little about options that make life with disability valuable. We know that the misplaced pity and pessimism of such doctors is reinforced by the medical institutions surrounding them, the policies that guide them, the health care funding system that rewards them for holding costs down, and the prevailing culture that influences their thinking about disability. That constitutes a formidable amount of bias against our lives. . . .

69. These concerns are not theoretical. The Dutch Regional Euthanasia Review Committees concluded in their 2013 Annual Report (at "Exhibit 32", p9):

The committees have established that there appears to be an increase in willingness among physicians to carry out euthanasia and assisted suicide in cases involving a mental disorder.

Wider Loss of Resources and Programmes for Disabled People

70. Finally, NDYA is concerned that the legalisation of euthanasia and physician assisted suicide will operate to remove much-needed resources from existing and planned programmes that are designed to help us as

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disabled people to live a full and satisfying life in our communities.

71. Craig Wallace of Lives Worth Living has spoken of this concern as follows (at "Exhibit 33"):

In the current world of rationed care and economic rationalism, it is not hard to imagine a situation where the availability of euthanasia becomes seen as a cheaper, easier, 'rational' option to providing intensive support, community living and care for those most vulnerable. Instead of having the support to make well-considered choices, the services that make life bearable could fall away and people with disabilities could be levered into taking their lives as the default option.

Euthanasia can become a euphemism which sanitises what is, essentially, suicide. ...

(F) Concluding Comments

- 72. Individual actions, which may ostensibly be seen as for humane purposes, can have inimical consequences for a whole category of people.
- 73. That is NDYA's concern here. Disabled people already are disvalued in thought word and deed. To people being systematically/regularly excluded and disvalued the actual legal availability of euthanasia and physician assisted suicide creates a climate of greater permission and tacit acceptance of outdated and inimical attitudes towards the value of disabled lives. It is likely to add further burden and undue risk to our lives. NDYA is concerned that if euthanasia and physician assisted suicide is an option, instead of working to improve the lives of people with disabilities, disabled people will be encouraged to die.
- NDYA has considerable empathy for the individual situation. As one of the authors has experienced first hand, brain tumours are not pleasant, and the side effects are very difficult. But the proposal of changes in the law on voluntary euthanasia and physician assisted suicide for an individual has too many negative consequences for disabled people, and is contrary to the Disability Convention.
- 75. As long as disabled people are disenfranchised and made to feel that we are burdens on society and on those who support us in the community, euthanasia and physician assisted suicide can not be a free choice for a disabled individual. It cannot be a choice made freely as long as people with

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disabilities are denied adequate healthcare, housing, transportation, personal support services, education, employment and community access.

76. For these reasons we echo the words of Jane (now Baroness) Campbell in her 2004 evidence to the UK House of Lords Select Committee (at "Exhibit 21", p235):

...whilst certain individual disabled and terminally ill people may see assisted dying as a necessary option, collectively ...we are utterly opposed to it.... Legalising assisted dying would condone this kind of discrimination. It will be harder to argue for much needed services if the counter-argument that we would be better off dead is given legitimacy.

Offer fight

Affirmed by Robyn Mary Hunt at Wellington this 8th day of May 2015 before me:

A Solicitor of the High Court of New Zealand

Nicole Jade Evans Solicitor Wellington

Affirmed by Wendi AlisonWicks at Wellington this 8th day of May 2015 before me:

A Solicitor of the High Court of New Zealand

Nicole Jade Evans Solicitor Wellington