Carers and human rights:
the parallel struggles of
disabled people & carers
for equal treatment.

Professor Luke Clements

Does he take sugar (1977)

Disabled people –
• Disability services sole responsibility
• Services and sympathy
• Handicapped cripples
• Needed ‘looking after’
Does he take sugar (1977)

Disabled peoples’ movement

1. The development of an identity
2. A narrative (of oppression); and
3. A creed.

Incredulity disability as a protective status

- Unlike – race and sex

Incredulity that disability as a human rights issue

- US Rehabilitation Act 1973
- Australia Disability Discrimination Act 1992
- UK Disability Discrimination Act 1995
- EU Equal Treatment Directive 2000/78/EC
- UN CRPD 2006

Now ‘self evident’
Does your carer take sugar?

Carers

- Disability services sole responsibility;
- Support and sympathy;

To become a rights movement they need:

1. the development of an identity;
2. a narrative (of oppression);
3. a creed.

Carer Identity?

USA ~ Filial responsibility laws in Alaska, Arkansas, California, Connecticut, Delaware, Georgia, Idaho, Indiana, Iowa, Kentucky, Louisiana, Maryland, Massachusetts, Mississippi, Montana, Nevada, New Hampshire, New Jersey, North Carolina, North Dakota, Ohio, Oregon, Pennsylvania, Rhode Island, South Dakota, Tennessee, Utah, Vermont, Virginia, and West Virginia

Germany ~ para 1601 Civil Code Bürgerliches Gesetzbuch

Singapore ~ The Maintenance of Parents Act 1995 (Cap 167B)

Ghana ~ customary law: eg *Quartey v. Martey & Another (1959)*

India ~ Maintenance and Welfare of Parents and Senior Citizens Act 2007

Taiwan ~ Article 1114 of the Civil Code (1929)
Self - identity?

The development recognition legislation
- UK Carers (Recognition & Services) Act 1995;
- NSW Carers (Recognition) Act 2010;

Widespread ‘compensatory’ measures
- Hungary Social Welfare Act 1993
- South Africa s7(a) Social Assistance Act 2004

Burgeoning number of Carer NGOs

A Narrative of oppression?

Stark evidence:
- Adverse health (depression, stress etc) & especially for young carers and carers looking after people with mental health difficulties
- Having to give up work to care
- Financial worries affecting their health
- Carers in debt
- Carers going without – especially parent carers;
  - heating,
  - Food
A Narrative of oppression?

Carers represent one of the most socially excluded groups of people in the UK

*Breaking the Cycle. A report by the Social Exclusion Unit (Office of the Deputy Prime Minister 2004)*

Associative Discrimination
Associative Discrimination

Resistance to carers as a protected category
Race, sex, disability – innate
Carers – ‘choose’

*Coleman v. Attridge Law* ECJ (2008)

UK Equality Act 2010, s13

Australia Draft Anti-Discrimination and Human Rights Bill 2012 s19 (4)(a) and s45

Now ‘self evident’ (almost)
But surely not a matter for ‘human rights?’

Caring as a human right?

Non-lawyers have spoken of caring as a proper subject for human rights discourse

Robin West (2002) ‘The right to care’

What is the point?

• Changes the political debate;
• Human rights v. Neoliberalism;
• eg ‘economic arguments
• cf disability discourse (independent living);
• No longer a sympathy; an ‘act of a generous state’
• But becomes an imperative; a state obligation
Caring as a human right?

Is there a structural difference between a right to care and a right to expression?

Right to private and family life

Article 17 ICCPR / Article 8 ECHR

Many ‘derived’ rights:

• A right to palliative care;
• A right to a livelihood;
• A right to development

Caring as a human right?


I simply do not see how … persons in [the disabled persons] situation can seek to rely upon the rights afforded to them by article 8 without allowing that their carers have … corresponding rights which have to be brought into the equation. If article 8 protects [the disabled persons] physical and psychological integrity – and it plainly does – then equally article 8(2) must … protect their carers’ physical and psychological integrity.
The Creed?

Martha Fineman ~ The Autonomy Myth

• Just as we have created environments based on needs of non-disabled people
• So too we have created environments based on the mythology of independent people
• A political system that 'deifies independence, self sufficiency & autonomy'
• But ‘all of us were dependent as children and many of us will be dependent as we age, become ill or suffer disabilities': dependency is inevitable
• When dependency work is uncompensated because it is gendered

Luke Clements,  ‘Does Your carer take Sugar’: Carers and human rights: the parallel struggles of disabled people and carers for equal treatment: