

coalition

The magazine of the Greater Manchester Coalition of Disabled People

February 2010

Price £3



Photograph courtesy of "Roaring Girl"

"What does it mean for us now?"

Plus:

THE STING

NHS Live

Poets Corner

RESISTANCE – which way the future?

Coalition, the official magazine of the Greater Manchester Coalition of Disabled People, aims to act as a forum for debate, analysis, and expression of opinion on all issues relating to disabled people.

Coalition does not knowingly publish any material which is offensive or demeaning to other oppressed groups of people.

All material published is subject to the approval of the GMCDP Magazine Working Group.

Please Note: Opinions expressed in this magazine do not necessarily reflect the views of the Greater Manchester Coalition of Disabled People.



Copyright:

We generally look favourably on requests from disabled people who want to reproduce items for campaigning or educational purposes, but permission is required by contacting the editor via the GMCDP office. If the item is for inclusion in a publication, we request that the following accompanies the item:

Coalition (issue no. and date)
the magazine produced by the
Greater Manchester Coalition
of Disabled People.

Coalition is published by the
Greater Manchester
Coalition of Disabled People

To contribute or subscribe,
please contact:

The Editor
GMCDP at BEVC,
(Business
Employment Venture
Centre)

AKED CLOSE
ARDWICK
MANCHESTER
M12 4AN

Tel: 0161 273 5154

Fax: 0161 273 4164

Our New E-mail Address:
coalition@gmcdp.com

Subscriptions: £15 per year

Coalition

CONTENTS

Editorial comments	Pam Thomas	4
Scorpio		6
Life's Worth	Anne Plumb	12
NHS Live Wednesday 7 July 2004	Jane Campbell	20
An Invidious NHS:	Huda Bishara	24
Poets Corner		30
My life is unbearable - don't fix it, just kill me	Clair Lewis	32
Resistance – which way the future?	Liz Crow	40
Three pieces of the social 'care' jig-saw	Aowyn Amath	47

**GMCDP MAGAZINE
WORKING GROUP**

Lorraine Gradwell
Angela Madeley
Anne Rae
Jacqui Tracey
Neville Strowger

ACKNOWLEDGEMENTS

Guest Editor: **Pam Thomas**

Layout: **Dale Watts, Phil Samphire**

Poetry: **Nate Webb**

**Cover picture of the crew and
cast of "Resistance" looking at
the memorial in Berlin.**

Editorial comment

It is already a year since our friend Ken Lumb died in hospital. It is also 13 years since coalition had a special issue on Life Death and Rights, published at the start of the New Labour Government.

This issue is published as we face another land mark general election and wonder whether the hopes of 1997 came to fruition. Back then Ian Stanton wrote: "Given all the evidence which history offers, given the growing pressure to introduce different justifications for killing disabled people, I cannot believe that if the taking of human life is legalised it will not be abused. And that the main victims of this legalised murder will be disabled people." This point is just as valid today.

This issue is also about life and death but with a slant toward the National Health Service, social 'care' and the

way in which we as disabled people are portrayed as a burden to carers and the state, and the value of our lives is brought into question when we need health and social care.

Ken Lumb's widow Anne Plumb writes for us about the way in which the medical profession appeared to expect that Ken would prefer to die than be resuscitated. This is no isolated incident, Jane Campbell had a similar experience in 2004 and has given permission for her story to be reproduced in the magazine. The wider issues of the NHS that provide the setting for these stories is discussed by Huda Bishara, she highlights a mismatch between the basic values of the NHS and target driven practices.

Closely related to the assumption that disabled people' lives are not worth living, and so they would prefer to not have life saving treatment, is the assumption

that disabled people should be the only group in society to be assisted to commit suicide.

Clair Lewis discusses the thinking behind assisted suicide and the way in which a particular UK journalist promotes assisted suicide as a solution to the lack of support to achieve independent living. Those that think it is obvious that our deaths are far preferable to our lives share a philosophy with those who upheld euthanasia in the Nazi holocaust. Liz Crow gives the background to the exhibition and film *Resistance* which is about the holocaust and the relevance to us today.

That we are considered to be an annoyance and a burden is illustrated in Aowyn Amath three short pieces, where she talks about some of the daily battles we have in everyday life.

Pam Thomas (Guest Editor)



Please send your comments / write to:

Email: coalition@gmcdp.com

Or by post to:

GMCDP
BEVC
Aked Close
Ardwick
Manchester
M12 4AN

The Sting

Lords-a-limping

The furore over expenses and the shameful actions of MPs has shown little signs of abating. Independent bodies set-up to scrutinise future claims and to claw-back previously fraudulent claims are springing up on an almost daily basis.

Recent attention has shifted to the land of the living dead, or the House of Lords as it is officially known. Lords do not receive a wage but are entitled to claim generous attendance and overnight stay allowances. This has led to many Lords “clocking-in” for a couple of minutes before departing with a pocket load of cash (potentially up to £330 a day). A nice little earner if you also throw in first-

class train travel for the peer and their partner.



The Senior Salaries Review Board has recently announced plans to end

this practice and has proposed a number of changes including a proposed salary which removes the inconvenience of having to actually attend Parliament to “clock-in”. You’d think that our Lords and Masters would be skipping for joy, but oh no! The Great and the Good are furious that one of the proposals is to replace the right to first-class travel for their partners, who in future will only be entitled to travel second-class. It seems to have escaped the attention of these unelected dinosaurs that very few people are actually paid to take their partners to work with

them and there is always the option of them paying for an up-grade if they wish to continue to travel together (the option of both travelling second-class is obviously too preposterous to seriously be considered).

A little reported recommendation from the Board, described by Lord Peston as “one of the most appalling and nastiest”, is that in future disabled peers would be required to provide receipts to claim for mobility allowances.

There is nothing wrong in suggesting that claims for allowances should be backed-up by receipts, but there is something pretty odious about suggesting that only the mobility allowance should require proof of expenditure. Funnily enough I have failed to find any evidence of wide-spread fraud amongst the few Lords-a-limping, but obviously the

Senior Salaries Review Board knows better. Or could it just be another example of taking every opportunity to stick the boot in on disabled people which seems to be a favoured pursuit of those in and around the Palace of Westminster. I wonder how the Review Board, peers and MPs would react if they had to go through the same process many of us have to in order to claim allowances and benefits.

A plague on both your Houses.

Criminal Crip

Having declared the laudable aim of achieving equality for disabled people by 2025 it is somewhat amusing to read that Noddy (National Office for Disability Issues) is consulting on how this will be measured. Most measures of equality are judged against the common criteria of employment, pay,

education/qualifications and life expectancy. It would appear that using these measures will continue to be problematic long after the 2025 deadline has passed.

I would suggest that the answer lies in crime. There are two measures that could be adopted to see just how equal we have become; we should seek equality in the areas of being victims and perpetrators of crime.

Accurately measuring the numbers of crimes against disabled people will have the added benefit of getting the police and CPS to start taking hate-crimes seriously. It will also be beneficial in helping to determine how many disabled people are accurately living independently. How so? Disabled people living independently are more likely to report crime than those living with their

families or under the care of the local authority, where both physical and financial abuse, occur more frequently.

The most interesting measure of equality would, however, be in relation to committing crime. It's reassuring to see regular reports of disabled criminals. The electric scooter seems to be the vehicle of choice for the increasing numbers of crimi-crips.

It's not just drink-driving, dangerously slow driving on motorways and anti-social riding on pavements that bring these bandits to attention of the forces of law and order. "Deals-on-wheels" is the rapidly expanding crime-of-choice for the discerning crimi-crip.

We know that we are finally making our way in society when we have the mobility and independence needed to

become a villain. I also find it amusing that the majority of crimi-crips have absolutely no fear of the sanctions should they actually be caught and convicted; being sent to an institution which removes liberty is something that many of us already have experience of; at least the crimi-crip has the comfort of knowing that they have been locked up for something that they have done.

Stranger-danger

As the recession bites and crime increases, coupled with a very cold winter, it's reassuring to see that parts of the government are increasingly targeting "vulnerable adults" with advice on how to stay safe. Homewatch schemes, community safety officers, Social Services (or Adult Social Care as it now is – a discreet change in name which reflects the fact

that they now care but no longer provide a service!; Adult Social Services (ASS) would be even more apt) and community groups are all busy making sure that we don't open our doors to bogus-callers and that we don't freeze to death. Fantastic.

Unfortunately much of this good work is undone by agencies "commissioned" to provide home support. The constant turnover of home support workers, largely caused by the appalling wages and conditions offered by agencies, means that many disabled people are constantly expected to open their doors to strangers. The record currently stands at over 130 different visitors in a 6 month period – let me know if you can better this!



If you happen to have a key safe, increasingly popular for providers so that their staff don't have to waste time waiting for you to get to the door to let them in, you face the added danger of people knowing the code number. If the number was changed every-time someone left then no one would ever be able to remember it!

Imagine the chaos if we all followed the safety advice and rang Crimestoppers (0800555111) every-time a stranger came round to deliver support!

Care-less

Once the stranger has entered your house you then face a toss of the coin to determine what support you receive. Many support workers provide a brilliant service and manage to defy physics in stretching 15 minutes or half an hour

almost Dr-Who-like to provide the assistance that you have been assessed as needing. Unfortunately there are also the opposite who can take the same time to introduce themselves and fill in the attendance sheet; invariably telling the next stranger that is due to call that you were happy/ fine/ ok/ fed/ watered/ medicated/ washed/ dressed (delete as applicable); this all being decided telepathically as there is no time left to actually speak to you!

Apparently they seem to get a little upset when you write on the handover sheets your own assessment as to what support you haven't received. My favourite is to agree that I am "happy" – happy that the useless/ patronising/ controlling/ over-bearing/ over-familiar / work-shy (delete as applicable) tosser has gone and it's just as well

that I was ok/ fed/
watered/ medicated/
washed/ dressed before
they arrived.

Sounds familiar? Cut out
and keep this piece in a
prominent place around
the house – preferably
attached to the front of
your care plan.

I can't understand why
they seem to think that I
can be "difficult". I find it
"easy" to treat people as
they treat me.

You BEHRCs

I owe an apology to
Trevor Phillips and the
face-less Muppets who
comprise the (British)
Equality and Human
Rights Commission. I
have previously
suggested that BEHRC
has been an abject failure
and raised concern that
disabled people's issues
were being marginalised.
I was wrong. We are not
being marginalised at all
– we are now just being
totally ignored.

Things are so bad that
Dame Jane and Poodle

Bert have thrown in the
towel along with other
members of the disability
committee.

It's time for us to take a
leaf out of the book of Dr
Nutt, who recently quit as
a government advisor on
drugs in order to set-up
his own independent
advisory body free from
government interference.

Disabled people should
do the same to Clever
Trevor as Dr Nutt has
done to Gordon Brown.
There are enough people
who have knowledge of
the system gained from
involvement in DRC,
Noddy and BEHRC to
establish our own
"Committee". If we want
to be truly radical we
could even make it
democratic, open and
accountable. Now there's
an idea.

Scorpio
Watch Yer Boots



Life's Worth.

In this article **Anne Plumb** shows the reality of clinical policies for disabled people who want to live. She tells us the story of the way in which she fought with Ken Lumb to get life saving medical treatment.

How much do we know about so-called Medical Futility Policies? QALYs/QUALYs, (Quality Adjusted Life Years) have been around for quite some time. QALYs are defined as a quantitative measure, in terms of years of good quality of life, of the value of a medical procedure or service to a group of patients with similar medical conditions (1). They occasionally surface in discussions on prioritising scarce resources, such as organ transplants, or when NICE (National Institute for Clinical Excellence) declines to recommend an expensive medication for use in the NHS. But can emergency life-

saving treatment be withheld? On the face of it, this seems so, as our daughter, Hazel, and I discovered when my husband, Ken Lumb, was admitted to North Manchester General Hospital (NMGH) with a chest infection.

Hazel first encountered this when Ken had a respiratory arrest, that is, couldn't breathe. She was shocked to be asked if he would wish to be resuscitated and to justify her assertion that he would! Admittedly, having had muscular dystrophy since his late teens and being now in his 60s, he was rather thin, but he was actively involved in the Greater Manchester Coalition of Disabled People, edited Coalition and had a blossoming relationship with Hazel based, amongst other things, on wide interests in cinema, literature and art. He kept up his own considerable drawing skills. What would have occurred if Hazel had not happened to be present? We were not reassured when we encountered the doctor

again and she explained that 'he did look much older than he actually was'. Indeed, it bothers me, that to justify Ken's resuscitation, I'm having to portray him as *especially* worth saving.

Even worse was to follow. After another respiratory scare, an Intensive Care Unit (ICU) consultant, an Intensivist, told me that a mini tracheotomy he had performed (to assist with clearing Ken's chest) had gone well but any further treatment would not be a good idea. He was talking here about a full scale tracheotomy (intubation and invasive ventilation) to connect a ventilator. I'm getting medical here because, on the ward, we heard an addition to the better known DNR (Do Not Resuscitate). It was Do Not Intubate. I challenged the doctor's general assumptions about life using a ventilator. What began as a congenial meeting became less so. I told the consultant that, in the 1970s, Ken had publicly supported someone on a

ventilator (Syd Harrison) to be enabled to return home from hospital and that, at home, Ken had The Responaut Study which had explored the wishes of people in "Iron Lungs" (following polio) to go home. Exasperated, the doctor told me that, lawfully, he didn't have to carry out such treatment; that he had obtained an Expert Opinion from another doctor, based on some statistical research into outcomes for people with muscular dystrophy. At this point, we decided to get our own legal advice. Ken confirmed that to be assisted to die (this is how we saw it) was not his wish.



Ken and Hazel, St Annes
1985

I sent a message asking the consultant to clarify the legalities of withholding emergency treatment. The Christmas Holiday was approaching but I was told to make an appointment with his secretary “during working hours”. Instead, with the amazing help of a network of disabled friends and allies, we contacted a law firm, Leigh Day & Co, known for its human rights and disability work (they defend both a right to life and a right to die). At their intervention, the doctors changed tack though they did provide us with a hand-out which was supposed to establish that such treatment, in their view, would be “medically futile”. Although we did not realise it at the time, this had a distinctive framework. It told us what a definition of futility might be, i.e:

Where the benefit to the patient (chances of survival) are small; and the proposed treatment (based on a consensus view from clinical

experience) is that treatment will be burdensome to the patient (in terms of quality of life – mental and physical suffering), and outweighs any perceived benefit.

Three benefits were listed:

1. Death will be postponed
2. May buy time until some package of ventilatory support is set up at home.
3. Allows additional time to be spent with family (1-2 perceived by patient and family. 3 consensus view of medical staff).

Disbenefits (consensus view of staff) began with:

May have short lived false expectations of a living a long life’.

(The consensus view in the 1970s was that someone like Ken would be lucky to reach fifty!)

Complications that might develop were listed followed

by a longer list of 'mental suffering'. It was the list of mental suffering that we challenged. This included

'frustration as a result of a limited ability to communicate...likely to be distressing due to the dehumanising nature of ICU... "locked into treatment" from which he cannot then opt out...once tracheotomised ...(being) no longer eligible for non-invasive ventilatory support...Even if the Strategic health Authority agreed to fund and set up a mini ICU at home this would take at least a year from the start of an application....

(elsewhere 2 years is mentioned). It's clear that this took no account of Ken's personality, his approach to impairment and disability, his home situation and existing network of support. In what way is using a ventilator to assist with breathing any different to using a wheelchair

to get about, especially when there are now, for example, sophisticated communication and other technological aids to lessen the impact?

Disturbing as so-called ICU Psychosis may be - Ken had already asked about mice on the bed, a gorilla on the ward, rather enjoyed some Busby Berkeley dancers and tried to protect me from an elephant!- he was unfazed once he was told these hallucinations were a side effect of artificial ventilation. Just how general this handout was became even clearer when we got to speak to Chris Hughes for Derbyshire CIL, another real support to us, who had twice been in ICUs in Manchester and come through to tell the tale. Ventilator pneumonia was a real danger but in our outrage at these assumptions, we missed it on the list of physical complications.

Nevertheless, emergency treatment was still assured, until Ken was required to move to the Wythenshawe hospital where the so-called

Expert Opinion had originated, as our Primary Care Trust (PCT) had a contract with Wythenshawe to provide a Home Ventilation Service. Through our lawyers we sought reassurances that life saving treatment would be given to Ken there should it become necessary. This was not forthcoming. Our lawyers claimed that, on the basis of case law, this was unlawful. They also told us that it was incorrect that Ken would become “locked in treatment”, as they had been involved in a court case on this issue. Meanwhile, St. James, Leeds, agreed to

provide a Home Ventilation Service and any necessary life saving treatment that might be required, subject to the PCT funding it. Clearly, not all doctors are not agreed whether treatment would, or would not be, “medically futile”.

It struck us that here is a widespread – and disturbing – practice to persuade people in such situations that further

treatment would too “burdensome”. To people supporting assisted suicide it might seem the doctors were doing Ken and his family a favour, but we most definitely did not see it that way. I have since found out that this practice is indeed sanctioned, that NHS Trusts have guidelines (4) and that Futile Care was, in the States, ‘*the rage from 1996 to 2003*’. This is reported by Karen Ward in an article (2) She also writes that:

....when you find ‘futile care’, you know euthanasia proponents, also known as End of Life (EOL) and Right to Die (RTD) proponents have made inroads in promoting their concepts through healthcare seminars, and by changing legislative policy, as in Oregon and Texas. The language often used is “burden”, “quality”, “suffering”, “dignity” and “quality adjusted life year (QALY)”.

Later, she remarks that some

now simply refer to 'uselessness'. Consultants attend these international conferences.

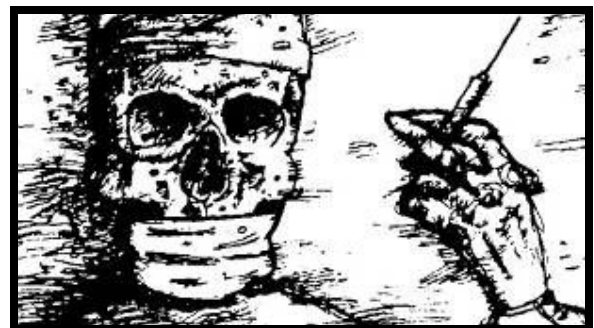
I also found, in a briefing. Does Patient Autonomy Only Apply If You Want To Die (3) that a question was raised in Parliament in 2002 by Dr. Iddon MP, following a programme on C4 on the application in the NHS of futile care theories. He asked that, rather than the courts and the medical profession leading the debate, wasn't it high time Parliament began to debate its policy? The response by a Mr Cook was;

"That sensitive and delicate issue has been raised on a number of occasions... such decisions are best left to the discretion of the medical doctors involved, who in hospitals throughout the country are daily faced with difficult judgments. I am not sure that high-profile political debate would assist them to make those difficult judgments."

[\(Hansard, 28 February cols. 850 and 851\).](#)

In this same briefing, Dr Colleen Clements, a Canadian professor of psychiatry, is quoted as saying in 1996:

"Patient wishes/choices are given supreme value when they are choices not to receive medical care, but are overridden when they are choices to receive medical care. Official opinion cries 'Medical futility' in going against patient wishes for medical care, thus saving money. It cries 'Patient Autonomy' in supporting patient wishes to terminate care, which also saves money."



NHS hospitals, like Pennine NHS, have guidelines relating to cardiopulmonary resuscitation, perhaps also to respiratory resuscitation?(4). Guidelines from the West Yorkshire Critical Care Network specifically mention that decisions should not be made solely on the basis of published research but should review individual circumstances, but I suspect this is limited to the same sort of assessment as above. Ken was subjected to an humiliating examination by Wythenshawe's muscular dystrophy specialist to establish exactly which form of muscular dystrophy he had – Ken had managed nearly 50 years unbothered by this – and to assess his muscle use. The doctor asked many personal and intrusive questions going back to Ken's childhood. I produced some photos of Ken over the years – in his early twenties, when we married, when Hazel was born, at her graduation, Ken at meetings... The specialist glanced at a couple then told me he was running

late and had to move on! We were presented with Ken's scores (bit low!) but what is their relevance when, with today's technology, you can do a great deal with a strong forefinger and thumb? Use a powered wheelchair, a phone, computer, and remote control to follow Manchester United and films and, even without such technology, draw, transplant seedlings ... and so on. No mention was made in the letter of what Ken could do. It was our guess that the whole purpose of the examination was to support the doctors' Expert Opinion that Ken didn't have much in the way of 'quality-adjusted life years' ahead of him.

On the face of it, doctors at NMGH were following guidelines - drawing up a list of benefits, and disbenefits, reaching consensus amongst themselves ...but could it be that what actually underlies the doctors' opinions is not solely medical but their own fears of impairment, perceptions of disability and cost implications? Sadly, with

added complications, Ken didn't make it home but, to his last breath, he was fighting for his life and against the system.

1. www.encyclopedia.com.

Dictionary of Nursing

2. Karen Ward. Are Medical Futility Policies Damaging Medicine?

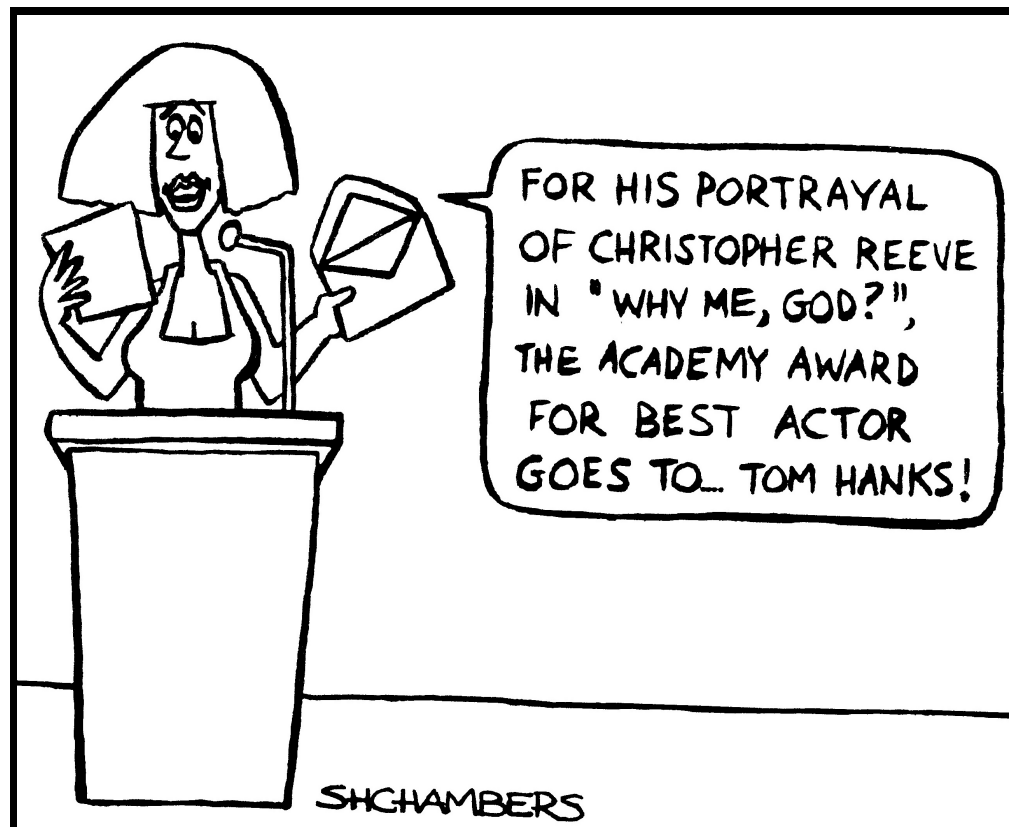
<http://www.northcountrygazette.org/articles/2007/012307FutilityLaws.html>

3. Does Patient Autonomy Only Apply If You Want To Die, Briefing paper. ALERT, 27 Walpole Street, London SW3 4 QS.

Aug 2006.

4. Pennine Care NHS. Policy for Decisions Relating to Cardiopulmonary Resuscitation/

From the Archives



NHS Live
Wednesday 7 July 2004

Here Baroness Campbell of Surbiton, Jane Campbell, has been at the forefront of the campaign to keep assisted suicide illegal. Here she tells of the time she nearly lost her life ...

I have had the best of times and the worst of times at the hands of the NHS. When I was born my mother was told to take me home and enjoy me because I would be dead within the year. Well here I am at 45 defying all the medical predictions! But it should be said that my survival is a combination of bloody-mindedness and fantastic healthcare. Particularly dispensed by one of the best respiratory units in the country and my fantastic consultant who celebrates disabled people's lives. But it hasn't always been that way.

Let me tell you a story about an experience I had:

In January 2003 I was rushed into A&E with

severe pneumonia in both lungs. I was very ill.

The consultant who was treating me said to me: 'You're very ill. If you go into respiratory failure I presume that you won't want to be resuscitated with a ventilator.' I was a little taken aback by this and said, 'Well, why?' He replied that the chances of weaning me off would be very remote – 'And you wouldn't want to live on a ventilator.' When I said that meant I would die and of course I want to be ventilated, he looked a little puzzled but let it drop. I thought that was the end of the matter.

The next day I was in intensive care when another consultant in a very senior position said the same thing. 'If you go into respiratory failure - and this looks likely - then I'm sure you won't want to be anywhere near a ventilator.' Again I protested but by now I was very scared.

My husband tore home, got a picture of me in my graduation gown receiving my doctorate, came back to the hospital and screamed that ‘This is my wife, not what you think she is and has. You do everything for her just as you would for anybody in this situation. She is young and has everything to live for.’

Then they changed their minds. Surely extreme measures should not be needed for me to access life-saving treatment. This should be my right – a right to life.

Nevertheless I forced myself to stay awake for the next 48 hours, fearful that if I went to sleep I’d never wake up.

So why was my experience 18 months ago so different from an able 44-year-old professional entering A&E at the peak of his or her career? Some of the answers lie in the negative beliefs about severe disability that are still so prevalent in our society.



Jane Campbell, DBE

Sadly society still sees disabled people as tragic victims of their condition or diagnosis. And in my case without dignity because I need all physical tasks done for me. It is not unusual for me to hear “I would rather be dead than live like that”.

Views such as these are just as likely to be held by the medical profession as anyone else.

After all they are just people drawn from a cross-section of society, subject to the same influences and negative



stereotyping around disability as anyone else.

It takes incredible strength to rise above these stereotypes and not to perceive them as fact. Some of us are fortunate enough to be able to challenge these assumptions. But stop and think: what if I couldn't speak up for myself, if I had no partner or carer that night, to fight for my right to live?

Progress has been made but there is still a long way to go before prejudices of the kind

I've described are eliminated. I would like to leave you with three messages:

1. That we start from the premise that all life is of equal value. That my life has equal value to my colleague Sir Nigel sitting next to me here, that we should be treated the same.

2. The best healthcare must be based on clinical need. It must not be dispensed on the basis of views about a patient's quality of life.

3. Options regarding treatment should be imparted to the patient and his/her supporters in a neutral, calm manner using open non-prejudicial language. People can only make appropriate choices when they have clear honest information.

I believe that acceptance and celebration of diversity at this level, is absolutely necessary for disabled people's equality and feelings of self worth and safety.

So long as society continues to see us in terms of our diagnosis, we will never have equal access to, or choice about, healthcare.

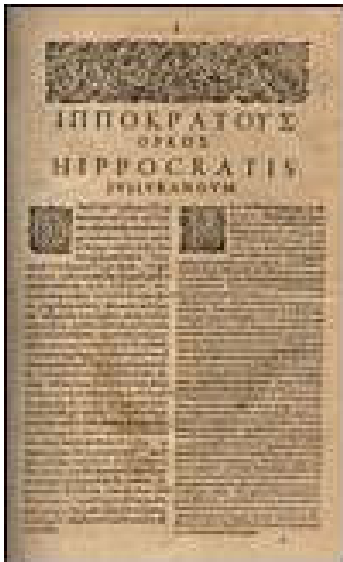
Find out more:

www.livingwithdignity.info/



An Invidious NHS: The Damage To Our Health Of Topsy-Turvy Values

Qualified doctors of medicine have to take an Oath – the Hippocratic Oath. **Huda Bishara** questions whether this Oath “to first do no harm” is applied when the patient is a disabled person.



The NHS is tantamount to a barrier-infested contagion spread by neglect and denial by those responsible for ensuring

its safety for all.

Before unpacking that loaded statement I shall begin by unloading the scope of this article by making the following points.

Firstly, though I refer to disabled people I do not speak on behalf of anyone

other than myself. I am also well aware that people from all backgrounds experience barriers in effectively accessing the NHS but there is no doubt in my mind, however, that those from marginalized groups (e.g. black, disabled, ‘working-class’ or elderly people to name a few) are comparatively worse off.

Secondly, I make no attempt to identify *how* the NHS disables us but take it as read that it does. Instead, I focus on *why* the NHS disables us by attempting to identify some of the values that underpin it in the hope that by understanding the nature of the beast and what makes it tick we might be better prepared for its bite.

Thirdly, whilst the NHS consists of numerous facilities, departments and bodies, my focus is on hospitals because I experience them to be the most disabling.

Fourthly, I make no distinction

between the NHS as a massive bureaucratic institution and the NHS as largely made up of isolated employees whose humanity often appears to have shutdown through a dangerous cocktail of indifference, demoralisation and alienation.

Fifthly, this is inevitably a 'negative' article in that it focuses on the damage inflicted on us: that does not deny the 'positive' work done by the NHS nor the reality of those who sing its praises. Given it affects our very existence at times of vulnerability the NHS will invariably arouse intense passions on either side of 'love' and 'hate'.

And lastly, I do not believe (though there are always exceptions) that NHS disablism is intentional (were that so it would be easier to eradicate) but rather that it stems from a deep-seated, all-pervasive ignorance that is difficult to combat because its invidious denial by NHS

employees is subtle and sophisticated (and here it is worth noting that 'invidious' (meaning discriminatory, unacceptable, unfair, harmful, likely to arouse resentment, ill will, offence, discontent, animosity or anger in others) comes from the Latin 'invidiosus' and 'invidia' meaning 'hostility').

However, acknowledging institutional disablism as largely unintentional does not justify or excuse it in a profession and service that has a moral and legal 'duty of care' towards those it claims to serve and whose credo is "first do no harm".

So why is the NHS harmful to the health of disabled people? What follows are some competing values operating within the NHS that I believe partially address this question.

As might be expected, competing values between a **medical** and a **social** approach to healthcare underpin much of the NHS's cultural mindset. Despite

policies to promote 'healthy living' and combat 'health inequalities' amongst 'disadvantaged' and 'deprived' sections of 'the community', the NHS seems incapable of effectively implementing these social-value agendas due to its medical-value priorities which prize **cure** over **prevention** and **performance targets** over **quality of life**. Health is seen primarily as 'fixing' and 'curing' whatever is 'wrong' with the human body: it is the absence of bodily 'imperfections'.

Given this one might expect that the NHS was perfectly suited to cater for disabled people and that it would be the last place on earth to harm us. After all, are we not exactly the kind of people the NHS needs to justify its existence? In reality, however, practice does not tally with theory as having *impairments* generally differs from *sickness* and, because these cannot be cured or fixed, the NHS is at loss when presented with us. Like dying or elderly people supposedly past their sell-by-

date, we do not appeal to NHS notions of 'successful outcomes' dictated by shifting targeted funding, professional rivalry and media spotlights. Even when we do present ourselves as 'sick' in a non-impairment related way the NHS is faced with a dilemma compounded by its fixation on our impairments: does it spend its finite resources on the '**worthy** **productive sick** who are potentially fixable (i.e. non-disabled people) or the '**unworthy** **unproductive sick** who cannot be fixed (i.e. disabled people)? Such perceptions belie a deeper arrogance: namely, that we deprive the medical profession of its sense of omnipotence and its insatiable hunger for accolades.

A reflection of this medical-value approach is the competing forces of **short-term** over **long-term** treatment with the short-term invariably winning to the detriment of those who would be better served by a healthcare that valued 'staying well' and the corresponding

long-term relationships that would be nurtured. This preference for sickness and short-term fix-it cures is also witnessed by the NHS's propensity to thrive on crisis and chaos: despite its aspirational name it would be more accurate to call the NHS the National Sickness Emergency Service.

Like anyone, disabled people need access to such emergency services but we are just as likely to need access to services that cater for our long-term impairment-related requirements: and yet, if the NHS fails us even in a **reactive** crisis in which it normally excels, how can it travel the distance with us in a more considered and **proactive** way?

Such a modus operandi results in an **unsustainable piecemeal** approach to healthcare that hinders a **sustainable integrated**, holistic approach. Scattered between various ivory towers incapable of effective joint-up teamwork we are forced into

exhausted and fragmented **passive objects** rather than **active subjects** of our treatment: and woe betide us if we try to reinstate our rightful position as intelligent subjects who know a thing or two about our own bodies! Attempts to assert our humanity and dignity are met with a toxic mix of offence and defence and we are expected to swallow their bitter pill of denial coated in patronising attitudes so characteristic of remote and disconnected tin gods strutting their stuff because they know best (and done, of course, with that all too familiar vacant passive-aggressive smile that will later label us as 'challenging' patients rather than ones reduced to invisibility).

Finally, there has been a fundamental value shift from the NHS being primarily a **public service** to being increasingly a **privatised business** albeit still under the guise of public ownership (it is worth reminding ourselves that the NHS will be in debt to the private sector for decades

to come as a result of all the new builds funded under private finance initiatives).

Nothing reflects this shift more than the compulsive mania to reach 'foundation trust' status and the hypocrisy of, on the one hand, claiming to promote the public appointments of lay people from marginalised groups to the positions of, for example, non-executive directors, and, on the other, effectively disbarring these very people by narrowing the selection criteria to those who have proven 'specialist' knowledge and experience in the fields of business, finance, accounting, legal services and IT. This can be contrasted to the past decade when people like myself were actively sought for both their patient experience and their background in 'equality and diversity'.

In conclusion, though my own leaning differs, I have no profound problems with much

of the values I have identified as underpinning the NHS. A medical-value base with some of its ramifications has a place in some measure and is not hostile to our health per se. What does disproportionately harm us as disabled people, however, is the gross imbalance of values, the unhealthy bias given to one set of values over their counterpart - what I have called 'topsy-turvy' values (and that is a generous assessment for some would assert that the social-values counterpart is non-existent). Perhaps most damaging of all, though, is the defensive denial of those who promote and collude with this imbalance thereby embedding ignorance and avoidance into the very fabric of the NHS and so perpetuating the invidious relationships that drive disablism instead of healing.

What we are up against

Mother 'injected son with heroin'

A mother accused of murdering her disabled son has described in court how she told him that she loved him before administering a heroin overdose.

Frances Inglis, 57, of Dagenham, Essex, denies murdering Thomas Inglis, 22, on 21 November 2008 and an earlier attempt to kill him on 4 September 2007.

Mr Inglis was fatally injected with heroin at his Hertfordshire care home.

His mother said: "I held him, told him I loved him, told him everything was going to be fine, took the syringe, and I injected him in his thigh and his arm.

Ms Inglis said: "I knew I had to help him. I asked myself what Tom would want. He wouldn't have wanted to live like this.

Ms Inglis, who said she used to visit her son twice a day, was asked by her barrister Sasha Wass QC about the "encouraging" prognosis described by consultant surgeon Ragu Vindlacheruvu.

He had suggested "that Tom would be running his own business, walking, talking, independent, totally opposed to what everyone else had said and what I had seen with my own eyes", said the defendant.

"All I saw was horror, pain and tragedy," she said.

She added: "I knew that Dr Vindlacheruvu was lying."

Story from BBC NEWS website

Poets Corner

This poem from **Nate Webb** appeared in Coalition in July 1997, the eve of the New Labour Government taking power. It is reproduced as we face another landmark general election and wonder about the policies of the next government.

Soul Repatriation Policy

“So keep them out of view!” they cry,
And “kill them!” if they’re not so bold.
For its everybody’s right to die.
If they don’t fit the mould.

So let the deformed and weak be slain,
And swept under carpets like trodden ants.
And let their rights be denied again,

We’ll give them ‘peace’,
we’ll get their thanks.

We can’t afford to support the weak,
So let society’s burden wane.
“It’s their choice to, surely seek,
Relief from what is surely pain”.

They are deficient can’t you see?
They can’t survive this world of ours
It’s good for them if they cannot be,
They’ll look better, remembered, with flowers.

We only want to help the few,
And if we help the world that’s great!
So let them die, those one’s who,
Want soul and body separate.

So stop the pretence,
stop the falsehoods, the
lies,
And tell us what you want
to say.
And let those who are
invalid die,
Purity tomorrow by killing
today.
We hear them crying
“help me die!”
Can't you see? What do
you mean “my staring
eyes”?



Hartheim Castle, a Nazi
"euthanasia" killing centre
in Austria.

This poem **by** Pastor
Niemöeller, 1946 often
appears with slight
variations in various
places, it packs a
powerful message.

First they came for

First they came for the
sick, the so-called
incurables,
And I did not speak out –
because I was not ill.

Then they came for the
Jews
And I did not speak out –
because I was not a Jew.

Then they came for the
communists
And I did not speak out –
because I was not a
communist.

Then they came for trade
unionists
And I did not speak out –
because I was not a trade
unionist.

Then they came for me.
And there was no one left
to speak out for me.

My life is unbearable - don't fix it, just kill me

It seems that when disabled people are having a rough time, there are some who suggest that the best solution is for them to be helped to die. This is a shortened version of an article by **Clair Lewis** that was originally published on the blog *Heresy Corner*.

Care staff had to help me out of bed this morning. It happens increasingly often these days, as my incurable disease and unfit body's slow ageing makes its mark. Some mornings, being lifted hurts so much I cry. It's only a matter of time before I end up wet in bed and need a commode and then a nappy. I regularly tip coffee down myself in the mornings because I can't hold a mug, and I still can't type properly because it takes two hours for my hands to warm up. I am only 36.

I'm pretty lucky actually. I am reminded almost every year by a social care manager that if I was childless I wouldn't qualify for care at all - in which case I'd be lying here alone with a bladder full to bursting, paralysed by pain and stiffness. Instead of writing and drinking coffee, I'd be trying to work out how to make it to the toilet before I wee. My life, what there was of it, would be pretty unbearable.

Nobody wants me to suffer. I don't want to suffer. My friends and colleagues don't want me to suffer. Neither do my doctors, my care manager, either of my beautiful girlfriends, or my three wonderful kids. If I died tomorrow, it would indeed end my suffering. If I said I wanted to commit suicide when it all gets too much, many people would support me and think the state should do it for me. If I said I wanted to die, would you rage at the state for not offering me a final solution?

It seems acceptable these days to suggest that being ('kept') alive is a kind of abuse. Polly Toynbee, for example, calls the 1961 Suicide Act - whose guidelines are now being re-written in the light of Debbie Purdy's case - "an instrument of state torture". She notes that "every poll in the last decade has shown between 74% and 87% of the public want the terminally ill to have the right to ask a doctor for a peaceful death."

The majority of the public are not disabled and not sick, so they have no direct knowledge of the subject. Their opinions are based on such things as prejudice fed by the media and government, witnessing the neglect of people they know or fearful fantasies about their own potential suffering.

Many support the idea of death clinics because they believe that most severely sick and disabled people want to end their lives, and just

couldn't do it themselves. In that case, why don't they simply direct their electric wheelchairs into the nearest river?

If a healthy, non-disabled friend told you that their life was unbearable, and asked you to kill them, and they were really serious, would you help them to find a way to die? Or, would you ask them why and offer them support? Would you maybe suggest solutions to the problems causing their misery? Would you send them to the doctor? Faced with a suicidal patient who is physically healthy, a doctor will most likely offer antidepressants; if your friend is lucky they may even get therapy to help them look into how they could feel better and what could improve their life.

The help offered to people with such feelings is often inadequate - patients who have slashed their arms in miserable failed suicide attempts are sometimes patched up and sent home

from casualty with no further support. But however strapped for cash the health service is one thing they won't do is offer to finish the job off properly. There's a reason for that - our healthcare system is here to save lives, to treat and cure. The Hippocratic Oath states that quite clearly. Thanks to doctors' traditional ethics - and their knowledge of the real issues people face - we currently don't have a healthcare system that aids and abets suicide. Thank goodness!

Suicidal tendencies are not exclusive to disabled or sick people. Lots of people who have lives filled with struggle or abuse, people who feel their lives are worthless, or who are having a miserable life, feel they want to end it all. But in the general population suicide attempts are seen as a cry for help, whose solution is to offer people help to live. Only people with physical health problems or impairment are ever seen as being mentally competent when they

want to kill themselves.

So why do politicians and campaigners propose suicide clinics exclusively for us? My friend Liz Crow, a filmmaker, artist and disabled activist, recently graced Anthony Gormley's Fourth Plinth in full Nazi regalia to point out the similarity between today's discussions and the eugenics promoted by the Third Reich. She comments in the film "Protest on the plinth"

They put across the idea of disabled people as suffering and deserving of mercy killing, in other words they're doing us a favour, by putting us out of our misery. Or where that doesn't work, they put us across as an economic burden and therefore it's in the interests of families and our nation and so on, to kill us. Three hundred and forty thousand people live in institutions in the UK. Underlying all of that is still the same set of values, about us as other, and lesser.

Despite the slow march towards equal rights for disabled people and people with long term illnesses, the government would prefer to ration healthcare, while social services are underfunded to the point that they now refuse support to anyone not in serious crisis. Meanwhile, the media are running ahead, misleading the public that disabled people's lives are terrible. They rarely consider the reasons, other than our impairments, why we might be having such a bad time. Social isolation, abuse, lack of equipment, being dumped in institutions, lack of opportunity, poor healthcare, insufficient support, and



Clair and fellow activists protesting outside the House of Lords

inaccessible housing all contribute to making people feel their lives are not worth living.

Many disabled and sick people fight every day for the right services to improve their lives. Many are isolated, locked away, or go without vital things they need - much of our suffering is not just related to our state of health. It's easy for the newly disabled to feel intimidated and undervalue what difference support makes, and maybe it's just easier to die than trying it out while they are still struggling with the trauma of a changing body, but I believe everyone deserves a chance at living before taking the permanent way out.

The public has an image of us as pathetic victims of charity, tragic but brave, lazy work-shy scroungers, a drain on the state, burdened with a fate worse than death, fit for abortion, even subhuman. People are so terrified of

becoming one of us that some of them want to book in their suicides now. You think I'm exaggerating? Someone came up to me recently when I was out in my wheelchair said "I'd kill myself, if I was like you". (It wasn't the first time. My response these days is "I pity you, coward").

I believe the root of public opinion is fear of suffering - and I agree that nobody wants to suffer. So why are we not looking for solutions which do not involve people having to die? The concept of liberating people from suffering by offering them fatal medications is more like an idea for a horror movie than a social policy.

It may help the public to swallow this idea, now that as a population we have quietly taken up the state's unique offer to investigate all pregnant women to identify and terminate unborn children with 'defects' any time until birth, even in cases when those infants could survive

unaided. Parents have morally accepted that disabled lives are not worth living, and are voting with their feet, or rather, the live contents of their wombs. It is seen as the socially responsible thing to do; even that parents are the cause of our family's suffering if they do not take this morbid way out. I think it is utterly shameful that people feel this is their only option. Parents deserve a real choice, which includes the choice to have their disabled child welcomed and included.

The philosopher Peter Singer goes further: he puts forward the argument that it should be ok to kill disabled infants after birth if it's for the greater good. And he's got a point. If we accept the above program, what's the difference? Other people are starting to wonder if it is acceptable to use the same ideas later in life, to effectively "liberate" people from torturous existences by ending their lives.

Disabled adults are

volunteering to die, in many cases because it's easier for everyone concerned than living. According to the US anti assisted suicide organisation Not Dead Yet say, the primary reason for people wanting to die is the feeling of being a burden. Polly Toynbee seems to agree: "Besides, the loss of independence and becoming a burden to others may be a valid part of the reason why someone feels life has become undignified and past bearing."

Absolutely, it is natural that this makes people feel awful - but I want independence and dignity in life, not to be given drugs to kill myself! Similarly, I feel angry that families do not automatically get the support that would prevent anyone becoming a burden. We certainly have the capacity to do this, if government chose to release the funding.

Polly Toynbee herself, quoting the National Council for Palliative Care admits that

"the least affluent get the least care." It seems a shame that in the face of this evidence she concludes that assisted suicide clinics are the answer. But I suppose that's not entirely surprising for someone who once wrote that "the right to life is not an absolute. It is inextricably and untidily linked in almost every case with social and psychological considerations, as well as the money that might have bought more health and happiness elsewhere."

Let's get the "death with dignity" myth smashed once and for all. No one gets dignity in death. Being dead simply cannot give the dead person more dignity, still less a better quality of life - so suicide cannot be the answer to the question of how people's dignity and quality of life is improved.

Whilst it is true that death would ease my suffering, it would also end my life, leave my children motherless and

homeless, break my lovers' hearts and end my usefulness to society. I don't want to die, I have already faced that possibility once and the value of every day of my life is immense. The benefits of living outweigh the consequences of my death a hundredfold - what price a mother? It's not a tough decision.

One day, I will die, like all other humans, and if I wanted to die at my own hands in this country I already have a right to commit suicide. If I want to take advantage of that one day, I will, and in almost all situations of possible illness there are ways to do it - as long as I continue to have independent living - the healthcare, support, equipment, housing and access I need to life and the living.

My body is still deteriorating. But my independence is going to tangibly improve next week when I'll be drinking coffee from something resembling a

baby's beaker in the mornings, so I don't have to have my care staff hold the cup and straw, or burn myself. I am also awaiting equipment so I can get up without human assistance and go to the toilet when I wake, on foot or using my wheelchair, depending what suits. All by myself.

These are just some simple examples of how the right support or equipment increases my ability to have a decent life, but I could list many more. These are the things that give me a shot at equality in life, the things which enable me to participate and have value as a human being in society.

I think our current working population ought to reject government and media fear-mongering, which lets the state off the hook, and ask the government for a better deal than death for their money, for those whose suicidal feelings are usually caused by neglect. I can't point you to accurate figures on this, as it's not in

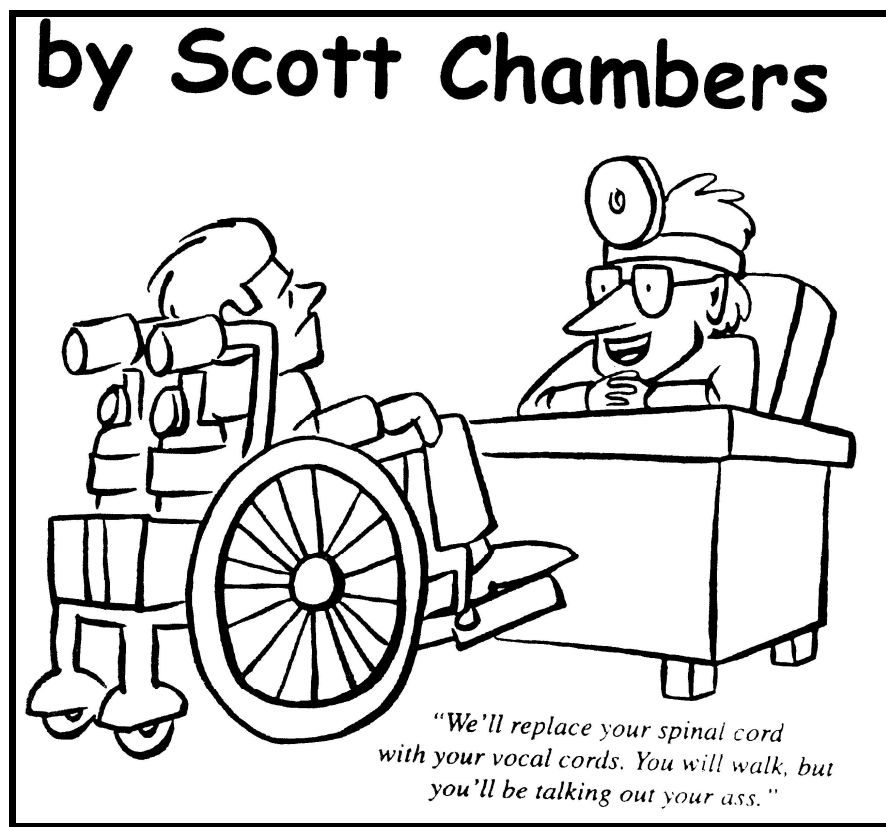
the interests of the state purse to study it. What I can tell you is, that in over a decade of experience of disability rights activism I have met hundreds of disabled people and people with serious illnesses, none of whom are privileged enough to be suffering from their illness or impairment alone.

For all those reading who still think we need suicide clinics, I ask you this. Are you happy to support the idea, knowing that one day someone might facilitate you or others to die,

at least in part, due to external factors which could be changed? If not, then this is the time to secure all our futures by fighting against these clinics and deciding to fight for inclusion, independent living and assistance to live, not assistance to die.

Full article available at:

<http://heresycorner.blogspot.com/2009/08/my-life-is-unbearable-dont-fix-it-just.html>



RESISTANCE – which way the future?

Back in August, artist and activist **Liz Crow** sat on the Fourth Plinth on a crowded Saturday night in Trafalgar Square as part of Anthony Gormley's *One & Other* project. She sat on her wheelchair wearing full Nazi regalia to draw attention to a hidden history and the message it holds for us all today.

Her performance on the plinth was part of a larger film-based project which is touring the UK and internationally.

Resistance: which way the future? explores the Nazi programme that targeted disabled people, whilst reflecting on what this history means for us now and inviting audiences to shape things to come. This article is from the interpretation sheet for the installation.

Resistance is a powerful, honest and hopeful work that transports us from a little-known but significant moment in our history to the present day, inviting us to reflect on how we can shape a better future. *Resistance* reveals the horrors of Aktion-T4 and asks what this period of history means for us now, disabled or not. How can we learn from these terrible events to shape a society that delights in diversity?

“Art as it should be - relevant to our lives, opening our minds.”



Historical Background

In September 1939, Hitler authorised Aktion-T4, a programme of mass-

murder targeting disabled people. By the end of the Second World War, more than quarter of a million disabled people had been killed.

For decades, international interest in eugenics had been building. Eugenics is the belief that the human race can be improved by encouraging people with 'desirable' physical characteristics to reproduce and preventing those with 'undesirable' characteristics from doing so.

The rise of Nazism in Germany made it possible to move from eugenic theory to systematic practice. In order to create a 'perfect' race of people possessing similar physical characteristics, the Nazis' attempted to remove disabled people

from the national gene pool.

When Hitler came to power in 1933, he introduced a series of measures to stop a new generation from inheriting impairments from their parents. These included placing disabled people into institutions, compulsory sterilisations, a ban on marriages between people with certain impairments, and the abortion of babies with impairments. On 1 September 1939, these were overtaken by Aktion-T4, a wholesale attempt to wipe out disabled people and the first chapter of the Nazi genocide.

Public health officials were required to register disabled people and basic information was sent to Aktion-T4 headquarters where three doctors selected those to

be killed. Being a member of the Nazi party didn't exempt disabled people from persecution, just as being a disabled person didn't stop Nazi officials from being persecutors. Patient lists were sent to 'observation institutions' where those selected were made ready for transfer to 'euthanasia institutions' transported in buses like the one in the drama Resistance.

On arrival patients had a medical examination, which allowed the doctor to identify a plausible 'cause of death'.

Photographs were taken of the patients to record their 'physical inferiority'. This was supposedly for 'scientific research', but was actually for use as propaganda to justify the programme. Patients were then shown into a darkened 'shower room', which held between 40

and 150 people, and the door was sealed.

A doctor released poisonous carbon monoxide gas into the room and observed as the patients died over a period of around ten minutes. The patients were then piled up next to the cremation ovens.



The "Shower Room"

Although Aktion-T4 was to be kept secret from the general public, people began to discover the truth. Local people saw the smoke of the cremation chimneys and smelled burning flesh, while relatives noticed

anomalies on death certificates.

In the small town of Absberg, disabled residents refused to board the bus and, according to the local Nazi leader, were taken away 'in the most conspicuous manner imaginable'. Dismayed townspeople assisted their friends and neighbours in their struggle against the guards. Hitler was concerned that this resistance would damage support for the regime and brought the official killing to an end in 1941.

At least 70,000 disabled people were killed during the official Aktion-T4 programme but this was also followed by an unofficial period of 'wild euthanasia' in which individual medics carried out their own killings in institutions

throughout Germany using starvation, poisoning, shooting and electric shock treatments. The final death toll is estimated at 250,000 but this number could well be higher, since many disabled people who were slaughtered in concentration camps do not appear in these statistics.

There are almost no first-hand accounts from disabled people affected by Aktion-T4 and confidentiality issues mean that medical records cannot be released. In the Nuremberg Trials, conducted by the Allies following the surrender of Germany, no disabled people were called as witnesses.

Dr Karl Brandt, one of the main perpetrators of Aktion-T4, was found guilty of crimes against

humanity and executed along with six others, although he maintained to the last that the programme was an act of mercy. He said, "I am fully conscious that when I said "Yes" to euthanasia I did so with the deepest conviction, just as it is my conviction today, that it was right." Only a small number of doctors and nurses who participated were prosecuted. Having acquitted a psychiatrist who watched his patients die through a peephole in a gas chamber, the court concluded: "we deal with a certain human weakness which does not as yet deserve moral condemnation."



Still from "Resistance"

The Chairman of the commission that ran the 'Children's Program' escaped punishment and published a book in 1962



The grey buses that transported people to the death centres

stating the case for the euthanasia of disabled children. As recently as the mid 1990s physicians active in Aktion-T4 were practising medicine and teaching in universities.

"I found that the experience [of Resistance] challenged my attitudes, both to the Holocaust and to disability, but in a way that did not leave me feeling guilty...it left me

feeling optimistic and unity and progress are possible.”

What does it mean for us now?

The historical drama in *Resistance* is based on real events. The protagonist Elise finds the courage and determination to resist oppression and discrimination. But what can we do?

In a time of rising hate crime against disabled people and a society that still holds numerous physical barriers and prejudices, it can seem overwhelming. Increased pre-natal screening and the abortion of foetuses with impairments, and hurried measures to legalise assisted suicide raise questions about the value of disabled people's lives and even their right to exist. Even

when we want to do the right thing, it can be hard to know where to begin. Yet, as one of the voices in the installation says, 'If no one speaks out, then nothing changes.'

'I cannot be silent. We can't afford to be silent. We need to fill our space.

We need people to know we're here because if we begin to disappear as we've done in the past, we need people to notice that we're missing. We need nondisabled people to be our allies. This isn't an issue about disabled people for just disabled people. This is an issue about society.'

By acknowledging inequalities, we can begin to address them. Put yourself in the position of another and notice the inconveniences and injustices they face. Imagine how you would

want to be supported. If you could do just one thing, what would it be? We all make a unique contribution to society; we can all make our own resistance.

“A great sense of hope and alliance between the disabled and non-disabled communities fills the work.”

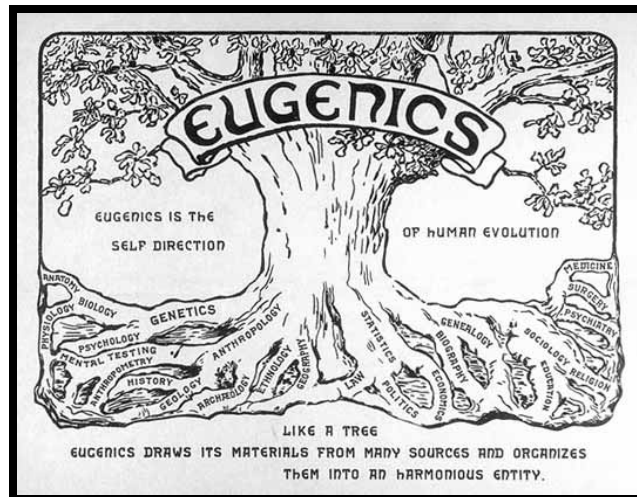
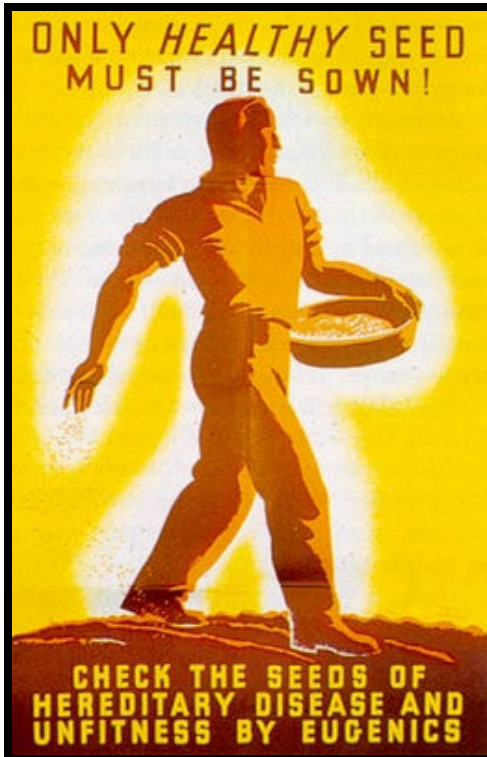


Text and photos courtesy of Roaring Girl

Resistance will be in Mansfield from 20 April to 1 May – check the website for opening hours.

After that, it travels to the Smithsonian in Washington DC from June to September, before returning to the UK.

Find out more:
www.roaring-girl.com



Two images from the 1930's promoting the Eugenics society

1, 2 3, 4 5, once I caught a PA alive

There is a link between the pressure for euthanasia and assisted suicide and disabled people's wish to not be a burden. That disabled people are placed in situations where they may feel a burden is illustrated in these three related short articles by **Aowyn Amath**.

Liz Carr's very witty discussion of her experience of employing Personal Assistants, although entertaining, led me to think about the steps before that – actually getting the resources to be able to employ Personal Assistants (PA's).

Unlike Liz, I have only been employing PA's for about 6 years, and during

that time I've had 2 assessments with Social Services departments in 2 cities – very different experiences.

As I discussed in a previous "Coalition" article about Fare Access to Care Services, my second Community Care Assessment was initially dominated by the Social Worker trying to "encourage" me to have informal, unpaid support from family and friends for the tasks I wanted a PA to do.

I am fortunate that I will argue my case, and challenge any suggestion that I should have informal, unpaid support, but I wonder how many disabled people there are who have caved in to pressure and agreed that they can ask friends or family for basic support that they would prefer a PA to do.

My concern was recently heightened when I considered applying for a job as “Broker” with a local authority team who support disabled people in receipt of Individual Budgets. One of the items on the Job Description was: Initiate and maintain supportive links with communities, as a possible means of providing “natural support”. I would question what this “natural support” is.

I would suggest there is no such thing as “natural support” in relation to disabled people beyond the age at which parents generally reduce, or cease to support their non-disabled children. Fair enough, sometimes mums and daughters or sons, sisters or brothers go shopping together, go out socially together, and do other things because they have a good

relationship and want to spend time with each other. Also, sometimes, parents or siblings help out with child care, or other temporary support when people are in difficult circumstances. But what it should not mean is disabled children “have to” go shopping or socialising with their parents or siblings because that is the only way they will get the support they need to do so, it should only happen if they want to. It also should not mean disabled children getting support regularly from their parents or siblings for the basics of life, cleaning, cooking, assistance with getting up, dressed, washing etc, reading post or communication assistance.

And as for communities. Yes, people pass the time of day in the street,

someone may hold the door open for the next person coming through the door, assist someone off the bus who has a pram, etc, but why should “communities” be expected to offer more than the casual, neighbourly support non-disabled people hope for? On the flip side of this coin, I have lost count of the number of disabled people I’ve heard say “but I can’t get a Personal Assistant, my husband/ wife/ partner/ parents/ family don’t want a stranger in the house.” My heart sinks when I hear this. It seems like yet another way by which those who should be closest to us, and want the best and most for us in life, are again those who restrict our independence.

As a PA user I can’t deny it is hard having a stranger in your home,

but if staff are chosen carefully and trained well, then it can work. Families would also need “training” to understand what the role of a Personal Assistant is as well, so that they do not unwittingly undermine the disabled employer’s authority over, or working relationship with, their PA.

And if our own resistance to becoming employers, the Social Worker’s determination to keep our support as minimal as possible, and our families’ resistance to someone else in the home isn’t enough, we then have the government’s policies to compete with when trying to get to the point where we can employ personal assistants.

I find it extremely worrying that the name of the latest government strategy relating to carers

is called: “The National Strategy for Carers - Carers at the heart of 21 century families and communities”. The Strategy suggests that by 2018, “carers will be respected as expert care partners”, should it not be that disabled people are respected as the experts in what “care” (if we must use that word) we need and want? I am also concerned about the fact that “carers” are placed at the “heart” of the community. Not only the place viewed as the central point, the organ that maintains life, but also the place traditionally related to feelings. All far too emotive!!

And finally, to depress you all even more – we have the looming credit crunch!!! It seems that nothing at the moment can be spoken or written of without reference to

the economy. But here it is relevant. So many local authorities have lost money at this time, it puts even more strain on already-stretched budgets.

As always, when I write in Coalition, I have no solutions to offer, just points to highlight. I wish I had solutions. I wish I could convince all those families that having a PA around, if managed well, can work for the benefit of all, I wish I could magic up more money so all disabled people can have the support they want, not just for absolutely basic need, but I can't. But I can hope for these in the future ...

Child Abuse, Slavery or Caring?

I was recently chatting to a friend about the whole

issue of disabled people, personal assistants and “carers”. He really shocked me by saying that he thinks having young people as carers is like child abuse. I did feel it was a bit strong, but then examined my thoughts and feelings towards the issue, and although not putting things quite so strongly, realised I do feel very, very uncomfortable with the concept, especially after seeing an advert on the TV over Christmas which was the story of a young woman who said she had been “caring for” her mother with MS since the age of 8, including changing catheter bags, assistance with other personal tasks and household work. This advert was being used to raise money for a children’s charity.

More emphasis and resources are going into

supporting “young carers”. What about resources to eradicate young carers?

Why, when it is illegal to employ children in paid work under 13 years old, and even children above that age cannot work legally without a permit from the local education authority, for more than 2 hours on a school day, or before 7am and after 7pm, does society think it is acceptable for “young carers” to support parents and siblings or other family members, often with very intimate tasks or hard house work? Why does society continue to reward such children with bravery awards, instead of taking the local Social Services to court for neglecting the personal assistance needs of the parent/sibling being supported to such a great extent that a child, if it were being paid for the

work it is doing, would be working illegally and probably to the detriment of its well-being?

How can a parent maintain a parental role, including disciplining a child, when the parent relies on the child for such support? It could lead to abusive situations arising when a child is not emotionally mature enough to avoid using its position of power over the parent. Most children rebel against their parents in one way or other, but being a “young carer” could exacerbate this situation and lead to bullying, emotional disfunction and at least considerable strain.

Who’s responsibility is it to stop this? Is it the parents’ responsibility to say “no, I don’t want this for my child and me”? How many parents would be afraid of contacting

Social Services for support in case their child is put on the “at risk register” or taken into care? Unfortunately, this still happens all too often, so who can blame the parent for continuing with an unsatisfactory situation by accepting their child’s support?

Should disabled people’s organisations be working with others, who we would not usually consider working with, such as carers’ organisations, to promote policies and support mechanisms for disabled parents which would stop this situation? Should we be thinking of taking local authorities to court when they continue to consider “young carers” as an acceptable part of the support mechanisms for disabled people? I say yes!!!

The IB-LETS

It's a dull, very cold winter's day, and I was sat here thinking about the theme for this mag, any solutions to how community care can be paid for?

What about a LETS? (Local Exchange and Trading Scheme) for Individual Budgets and Direct Payments.

For example, I had difficulty recruiting new staff this year, which means that I have a budget underspend. What if this underspend could go into a pot, and I say "OK, I would like to use this under spend next summer to have a PA to go on holiday". In the meantime another PA user temporarily needs more support. What if that PA user could draw on the pot for extra hours, committing to repaying

those hours back in, say, April, May and June.

That means my spare hours would be used now by someone who needs them, but I can draw on them when I want them as they will be paid back. Alternatively, what if the scheme had a "reserve fund", in which I could say "OK, I am not going to use all this underspend on that holiday, some can go into the reserve fund". That fund could be used to give another disabled person extra PA hours, or at least some PA hours, as I wouldn't be calling in those hours later on.

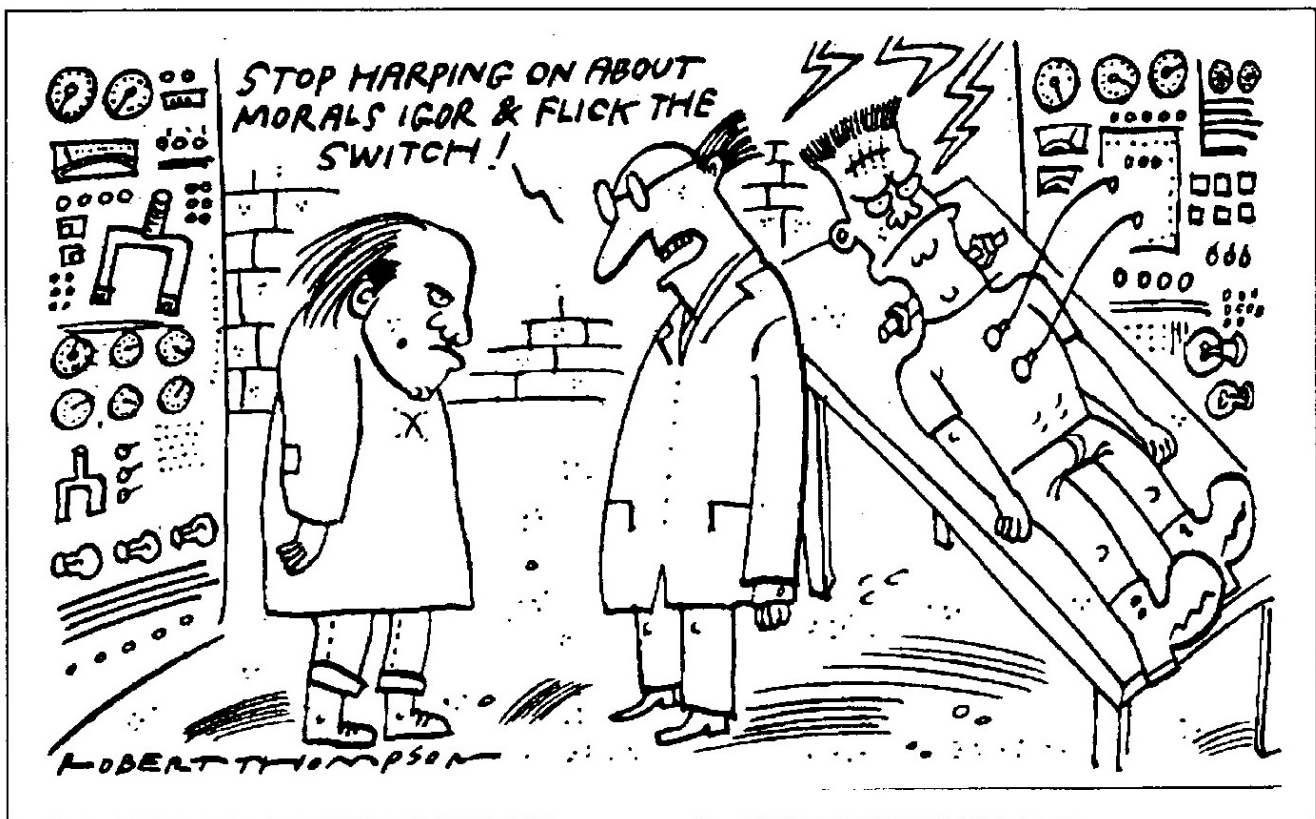
I know not all PA users have times when they use less than their assessed hours, but I know that I for one, would be delighted if I knew that any money I don't use, would go straight into a pot to give another disabled person the chance to have a PA.

Another example, I generally employ students, and for so few hours a week that they are not eligible for tax and National Insurance. This means I don't necessarily use the money that is set aside for employer contributions, and haven't

yet used the sick leave or bank holiday contingency. So what if that money could go into the "reserve pot" if I don't need it? those little bits of money could mount up.

Just a thought – anyone any others?

From The Archives



GMCDP PUBLICATIONS & MERCHANDISE



1



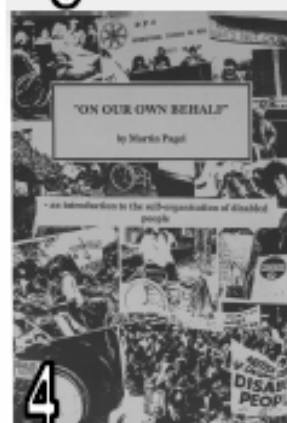
May 2005 Price £3



2



3



4

1. A Dangerous Woman
by Sue Napolitano
A collection of witty, pithy, poignant and most importantly of all, POLITICAL poems.
Price £2.50 + 75 p&p

2. Coalition Magazine
Price: £3 (Back Issues £1 + £1 p&p)

3. Disability Is ...
A 4 minute animation video made by young disabled people, exploring the issues around positive imagery and role models as experienced by young disabled people.
Price £20 to £50 + £4 p&p

4. On Our Own Behalf by Martin Pagel
A starting point for anyone interested in the growth of the Disabled People's movement.
Price: £2.50 + 60p p&p

5. "... distress or disability?"
by Anne Plumb
A discussion paper laying out some issues, arguments and history from a Mental Health System Survivor's point of view.
Price £2 to £5 + 60p p&p

6. Over To Us ... by Maureen Greene
A report of an advocacy project working with young disabled people living in residential institutions.
Price: £5.99 + £1.50 p&p



5



6

Where prices vary, this is dependent on the type of organization wishing to purchase items.
Please allow up to 14 days for delivery.
Please make cheques payable to:
GMCDP
GMCDP, (BEVC), Aked Close, Ardwick, Manchester M12 4AN.
Tel: 0161 273 5154
E mail: info@gmcdp.com



7. Positive Image Posters
 Produced by the Young Disabled Peoples Forum,
 Price £5 per set of 4 + £1.50p&p

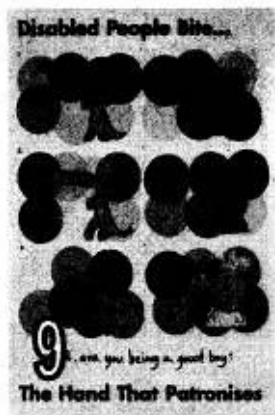
8. Disabled People Bite ... The Hand That Patronises (poster)
 A 594mm x 840mm poster taken from the 'Disability Is ...' animation video.
 Price £3.50 + £1.50 p&p

9. Disabled People Bite ... The Hand That Patronises (postcard)
 A full colour postcard taken from the 'Disability Is ...' animation video.
 Price £1 for a pack of 5 + 30p p&p



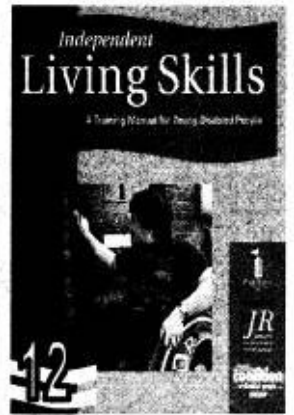
10. Take Action Now
 Set of 4 Positive Image posters designed by Jacqui Tracey.
 Price: £5 per set of 4 + £1.50 p&p

11. Peer Mentoring - A Good Practice Guide
 CD-Rom produced by the Young Disabled Peoples Forum, discussing the merits and practicalities of peer mentoring for young disabled people.
 Price: £10 to £20 + £2.00 P & P.
 Accompanying report available from Pavilion Publishing on 01273-623222 or by email info@pavpub.com



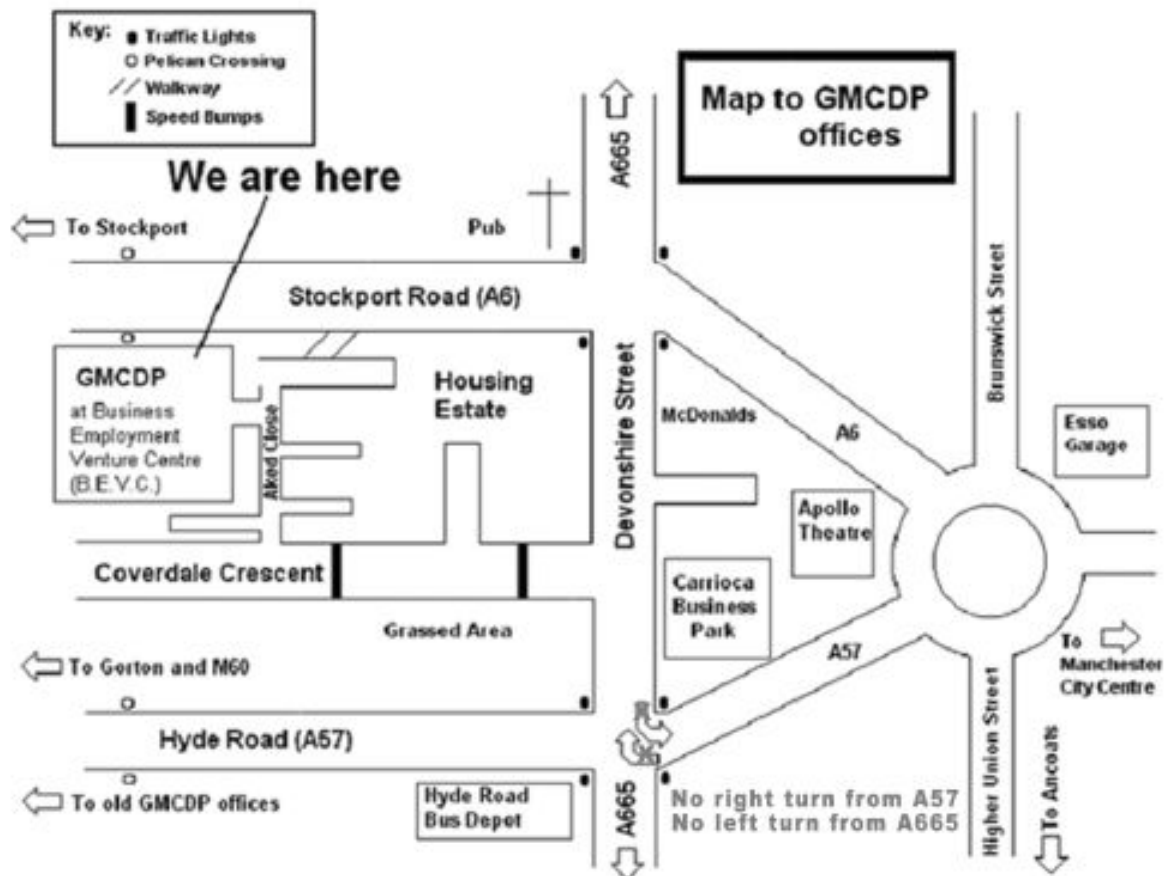
12. Independent Living Skills
 Training manual with video promoting independent living for young disabled people.
 Price £20 to £40 + £3.50 p&p

Where prices vary, this is dependent on the type of organization wishing to purchase items.
 Please allow up to 14 days for delivery.
 Please make cheques payable to:
GMCDP
GMCDP, (BEVC), Aked Close, Ardwick, Manchester M12 4AN.
 Tel: 0161 273 5154
 E mail: info@gmcdp.com



GREATER
MANCHESTER
coalition
— of disabled people —

GMCDP



**GMCDP, BEVC, Aked Close,
Ardwick, Manchester, M12 4AN
Voice & Text: 0161 273 5154
Fax: 0161 273 4164
E-mail: info@gmcdp.com**

All GMCDP publications are available in standard and large print, in Braille and on cassette tape.

