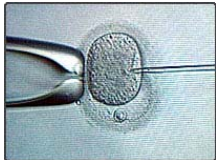


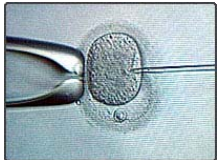
A Welfarist Account of Disability

Dr Guy Kahane

Professor Julian Savulescu

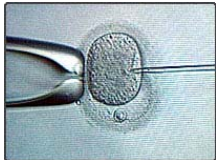


Disability



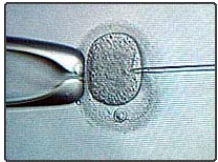
- 2 dominant concepts of disability
 1. Species Norm Model
 2. Social Model
- We propose a new concept:
 - ❖ Welfarist Model

Case 1. *The Famous Deaf Lesbians*



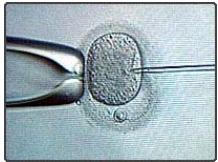
- In 2001, Sharon Duchesneau and Candy McCullough, a deaf lesbian couple had their second child Gauvin
- The women, who wanted to have a deaf child, conceived Gauvin through Artificial Insemination by Donor (AID), using sperm from a friend they knew to have five generations of inherited deafness in his family
- They argued that:
 - ❖ Deafness is an identity, not a medical affliction that needs to be fixed
 - ❖ The desire to have a deaf child is a natural outcome of the pride and self-acceptance many people have of being deaf
 - ❖ A hearing child would be a blessing, a deaf child would be a special blessing
 - ❖ They would be able to be better parents to a deaf child than to one who was hearing
 - ❖ The child would grow up to be a valued member of a real and supportive deaf community
- “Deafness is not a disability”

Case 2. Dwarfism



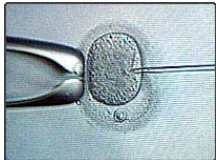
- Two achondroplastic dwarfs request PGD to select an embryo with dwarfism
- They argue that being little is not a disability, it is a difference.
- Their house and lifestyle have been modified for their short stature. They claim that they would be better able to rear a short child rather than a normal child. A dwarf child would have a better life with them.

Case 3 Body Integrity Identity Disorder



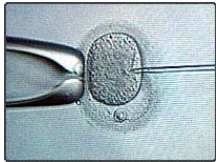
- John is a want-to-be amputee. He does not identify with a body with 4 limbs and requests an amputation.
 - ❖ attends conferences with amputees and is sexually attracted to them, wanting to be one of them.
 - ❖ has investigated seriously how to amputate his own leg below the knee.
 - ❖ has undergone extensive counselling and psychiatric therapy but the desire persists.
 - ❖ is depressed as a result of having 4 limbs and considering self-amputation
 - ❖ would use a prosthesis if amputation was provided.

Case 4 Ashley Case



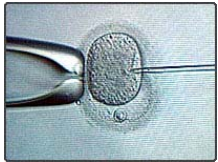
- ❖ Ashley, a nine-year old from Seattle who was born with static encephalopathy, a severe brain impairment that leaves her unable to walk, talk, eat, sit up or roll over.
 - will remain at a developmental level of a three month old baby
 - In 2004, high-dose estrogen therapy to stunt Ashley's growth, the removal of her uterus via hysterectomy to prevent menstrual discomfort, and the removal of her breast buds to limit the growth of her breasts.
 - Ashley's parents argue that the Ashley Treatment was intended "to improve our daughter's quality of life and not to convenience her caregivers.

Ashley's Parents



- "Ashley's smaller and lighter size makes it more possible to include her in the typical family life and activities that provide her with needed comfort, closeness, security and love: meal time, car trips, touch, snuggles, etc."

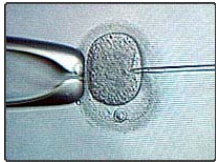
Case 5 Colour Blindness



- A watercolour painter develops a rare disorder where he goes colour blind, no longer able to distinguish between red and green

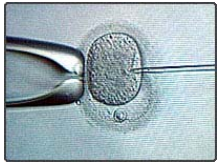


Case 6. IQ reduction



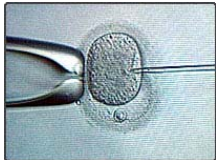
- A child is found to have a heart abnormality. Surgeons place the child on cardiac bypass to remove the lump. As a result of bypass, the child's IQ drops from 180 to 150. The lump turns out to be benign and surgery was not necessary
- When confronted by the parents, the surgeon says "He has plenty of points to spare."
- The parents sue, arguing that the doctor "disabled their child"

Case 7. Cynthia (after Daniels)



- Cynthia has extraordinary powers of understanding other people's emotions, displaying empathy, understanding what people need and responding to it.
- She could have made an ideal counsellor or doctor
- However she experienced a deprived upbringing and uses her powers to cheat and defraud elderly pensioners of their retirement savings
- She is eventually caught and gaoled for 10 years

1. Species Norm Account of Disability



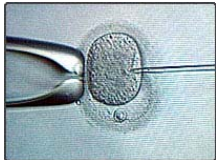
- **DisabilitySN**

A stable intrinsic property of subject S that deviates from the normal functioning of the species to which S belongs

- ❖ Problems

- Need to specify as sub-functioning: IQ 69 is intellectual disability but 71 is not, though need 90 to fill in a tax return
- Statistical norm is relative to time, place, etc
- Descriptive but not evaluative concept, but disability is part evaluative
 - We speak of people as *suffering* from a disability.
 - We take a disability to be a misfortune to those who suffer it, something that makes their life worse, and thus something that gives us reasons to try to avoid or correct it

*Evaluative Disability*SN



DisabilitySN+E

A stable intrinsic property of subject S that deviates from the normal functioning of the species to which S belongs, and *simply because of that* makes S's life go worse, and therefore gives reasons to avoid, regret and correct it.

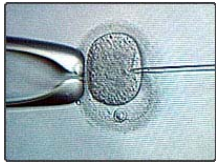
Problems:

Statistical norms have no intrinsic normative significance

Loss of hearing and sexual functioning are statistically and biologically normal with age, but still disabling

Because of effect on well-being

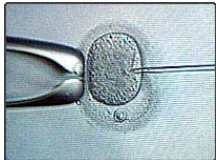
2. Social Model



Reject normative significance to statistical or biological deviations or DIFFERENCE or DIVERSITY

- "...a social discrimination that limits opportunities of persons of difference....[and] results only when physical difference is not accommodated by society." Tom Koch
- "Disadvantages are ... effects not of biomedical conditions of individuals, but rather of the socially created environment that is shared by disabled and nondisabled people. This environment... is so constructed that nondisabled people are privileged and disabled people penalized. Disability is a social problem that involves the discriminatory barriers that bar some people but not others from the goods that society has to offer." R. Amundson

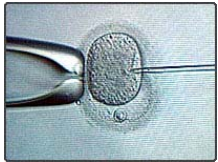
Social Model of Disability



DisabilitySM

A stable intrinsic property of subject S which (1) deviates from the normal functioning of the species to which S belongs (i.e. a disability_{SN}) *and* (2) which tends to reduce S's level of well-being *because* members of the society to which S belongs are prejudiced against such deviation from the normal

Social Model



- *because* of the entrenched use of the defective concept of disability_{SN+E}, use of this concept is self-confirming: disability_{SN} is bad because *treated* as bad. It's contingently bad because (contingently) treated as necessarily bad.
- Part of the suggestion is that, if most people stop using the concept disability_{SN+E} and instead use that of disability_{SM}, this would hopefully lead to a change in society with the result that there would no longer be anything that counts as disability_{SM}.

Wider Concept



Discriminated Trait

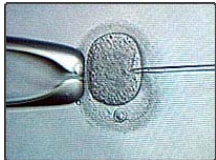


A stable property of subject S which tends to reduce S's level of well-being *because* members of the society to which S belongs are prejudiced towards people with this property

- ❖ Race/skin colour



Social Model



- DisabilitySM singles out a genuine form of harm
 - ❖ a harm for which many people are morally responsible

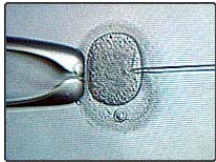


- The question is:
 - ❖ *does* this concept capture *everything* that might be said about the evaluative connection between disability and well-being that is enshrined in the everyday concept



Program on Ethics and the New Biosciences

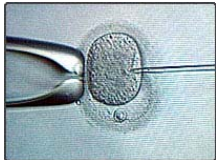
Problem



- Tautology to say that “[The environment... is so constructed that ... disabled people are penalized.”
- It makes no sense to say, of a country, that in this country disabledSM people are not discriminated against



The Welfarist Account

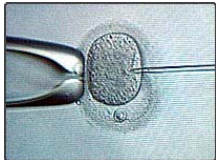


- The concept of disabilitySM is a species of discrimination
 - ❖ But discrimination is a species of the far broader concept of *the harmful*

The Harmful

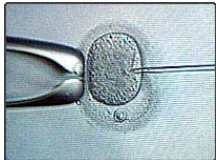
X is harmful = X leads, in circumstances C, to a reduction in person S's level of well-being

Harm and Harmful



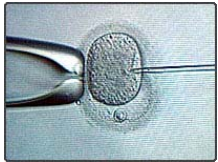
- One natural way to conceptualise harm is by the counterfactual:
 - ❖ X is harmful if, had X not been present, S's well-being would be higher.
 - ❖ X makes S worse-off than he would have otherwise been

Harm and Harmful



- Harm:
 - ❖ a person can be worse off if he feels more pain, achieves fewer of his aims and projects, or enjoys fewer deep relationships.
 - ❖ his life goes worse if it includes fewer of the components of well-being—if it includes more of what is *intrinsically good* for the person.
- Harmful
 - ❖ refers rather to what is *instrumentally bad* for a person—something not bad in itself but bad through its effects.
 - ❖ the harmful is what *leads to* harm.
- Some conditions are both harms *and* harmful.
 - ❖ Pain, for example, is bad in itself but, if strong enough, also stands in the way of a person's pursuit of his projects, or for that matter, from making use of opportunities for pleasure.

Harmful Trait

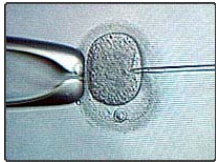


- Roughly, harmful things have their causal source:
 - ❖ In our surroundings:
 - natural environment
 - social environment
 - ❖ In ourselves
 - Psychology
 - Biology

Harmful Trait

A stable intrinsic property of subject S that leads to a reduction of S 's level of well-being in circumstances C

Welfarist Account



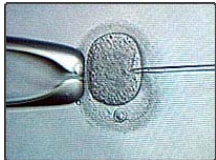
Disability_W



A stable physical or psychological property of subject *S* that leads to a reduction of *S*'s level of well-being in circumstances *C*



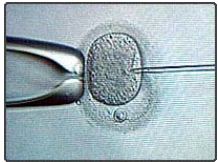
Features



1. Makes no reference to normality

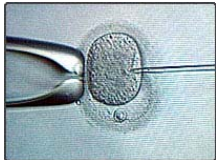
1. Whether or not a condition is normal or deviated from normality is not an intrinsic property of a person.
2. Illness would count as (or is best understood as) a disability^W
3. Harmful character traits—perhaps having a weak will, excessive stubbornness, lack of confidence—would all count as disabilities^W

2. Has an intrinsic normative dimension



- According to the everyday use, if something is a disability, then it is a misfortune to those who suffer from it, makes their life go worse, and gives reasons to correct it.
- DisabilityW achieves this through connection with well-being

3. Relative to person and context



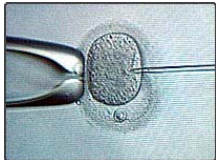
Disability W is relative to both persons and circumstances.

e.g. atopic tendency which leads to asthma in the developed world
protects against worm infestations in the undeveloped world.

Deafness would be a positive advantage in an environment of
loud and constant noise

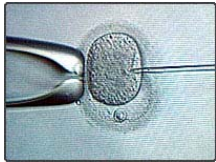
- ❖ The everyday concept doesn't have this relativity.
- ❖ It not only mistakenly implies that deviation from the species norm is bad, but also seems to imply that they are bad in themselves, quite independently of context.
- The concept of a disability W is, by contrast, context dependent.

Context Dependent



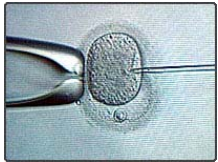
- Internal and external factors often interact.
 - ❖ For a wealthy and healthy person, blindness may not make a significant difference to well-being.
 - ❖ A poor person can be made much worse by being blind.
 - ❖ But, holding a person's blindness constant, we can ask whether poverty would reduce or increase their well-being.

Context Dependent



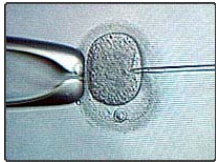
- On our account, it often makes little sense to ask of some condition, ‘Is this a disability?’
- In order to judge which conditions constitute a disability, we need to know what class of people is being referred to, and to predict what the likely context or environment is likely to be. There is no context-independent answer to such questions.

4. It's ubiquitous



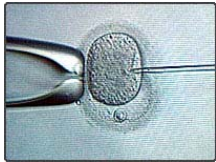
- One example of a disability is asthma.
 - ❖ Asthma makes breathing more difficult in certain environments commonly encountered in the developed world—dusty or smoky environments, or places with pets.
 - ❖ It can make it more difficult to enjoy the company of others or do physical activity if it is difficult to breathe.

Ubiquitous



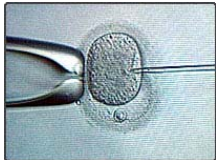
- ❖ It is a consequence of our account of disability that in this and similar ways, *all of us* can be said to suffer from disabilities
 - conditions inherent to our nature which reduce our well-being and make it more difficult to realise a good life.
 - Asthma, a lame foot, pig headedness, psychological biases and weakness of will are all disabilitiesW.

5. Relation to Disease and Illness



- Disease and illness can also be seen as subsets of disability.
 - ❖ The extent to which a disease is a disability determines the extent to which an ill person should be treated.
 - ❖ Some illnesses have so little impact on a person's life that such ill people have very little claim to treatment, despite the fact that their biological functioning might deviate from the species-typical norm.

6. Degree or threshold or threshold-and-degree concept?

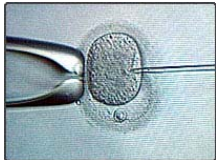


- Degree concept

- ❖ But the everyday concept is both a threshold and a degree concept.

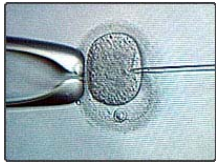
- light deviations from species norm, such as short-sightedness, don't count as disabilities.
- only more significant deviations, such as very poor sight or blindness, meet this threshold.
- But once something counts as a disability, it's often compared in seriousness to other disabilities.
 - Paralysis is said to be a more serious disability than deafness.

Degree concept



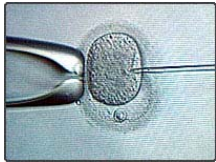
- Problem:
 - ❖ appears absurd to describe someone with an IQ of 160 as disabled just because some condition prevents her from having an IQ of 180.
- But compare unpleasant experiences and suffering:
 - Suffering is not a different kind of experience just a matter of degree
 - ❖ Relative scale: King Kong is small compared to T-Rex

Disability and Disadvantage



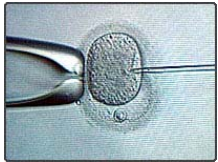
- ❖ People who suffer from significant disability W may require special facilities or financial support.
- ❖ Some people might prefer to use the word 'disadvantage' to refer to mild forms of disability W .
 - They would find it counter-intuitive to describe someone with less than perfect health or the intelligence of a genius as disabled in any way.
- ❖ **Disability W**
 - A stable intrinsic property of subject S that that leads to a *significant* reduction of S 's level of well-being in circumstances C

Relation to Everyday Concept



- The welfarist account preserves much of the evaluative dimension of the everyday concept, but drops its descriptive dimension
 - ❖ refers to instrumental, not intrinsic badness, and the badness is relative to person and circumstance.
- like the everyday concept, it refers to a stable physical or psychological condition, but there is no reference to either biological or statistical normality.
 - No reference, even, to the biological species of the subject.
 - Only to their well-being.

Why Revise?



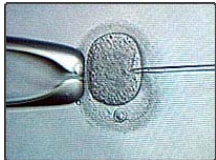
- Inclusive in just the right way.
 - ❖ Human Genome Project will show all of us disabled in some ways by our biology
- Not everyone disabled in the everyday sense would count as having disabilityW,
 - ❖ most people who count as normal have, to some degree, disabilitiesW.
 - ❖ It leaves out the irrelevant reference to normality.
 - ❖ it makes salient the normative continuity between stronger forms of disabilityW and the ubiquitous lighter forms that everyone has.

Relation to Other Accounts



- 1. DisabilitySN
 - ❖ it deviates greatly from SN's descriptive content.
 - ❖ Some people think that this is too radical a departure. That it's too inclusive of things that, intuitively, don't seem like disabilities at all.
 - ❖ Response: disabilityW as stating only a necessary condition for something's counting as a disability.
 - Some further condition must be met to get disability proper.

Hybrid Concept



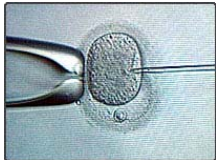
DisabilityW+SN

A stable intrinsic property of subject S that (1) deviates from the normal functioning of the species to which S belongs (i.e. a disabilitySN) *and* (2) leads to a reduction of S's level of well-being in circumstances C (i.e. a disabilityW)

❖ Problem:

- no very interesting connection between conditions (1) and (2).
- not the fact that it deviates from a species norm that makes a property detrimental to well-being

2. Disability_{SM}



- useful to narrow down disability_W so that it refers only to the effect a condition has on well-being that we get when we *subtract* the effect it has through social prejudice:



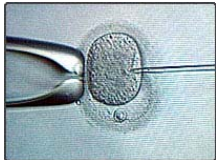
Disability_{W-SM}

A stable intrinsic property of subject S that tends to reduce S's level of well-being in circumstances C, *excluding* the effect that this condition has on well-being that is due to prejudice against S by members of S's society due to the deviation of this property from the normal functioning of the species to which S belongs

- We accept this
 - ❖ Race is not a disability
 - ❖ Natural vs Moral Evil

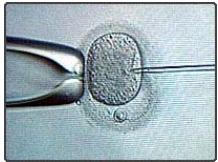


DisabilitySM



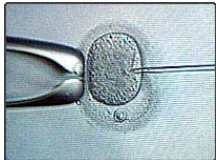
- For those who appeal to Disability SM, DisabilityW-SM is a null set.
- *All disability is the product of prejudice*
- But what is prejudice?

Prejudice



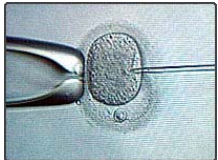
- Prejudice presumably involves negative attitudes and behaviour towards people with the trait in question.
 - ❖ *And* these must be attitudes that are not justified.
- But there are plenty of cases where we have very good reasons to have negative attitudes towards people with certain intrinsic traits – reasons, for example, to feel contempt precisely for people with prejudiced attitudes
 - ❖ Some negative attitudes are just

Prejudice



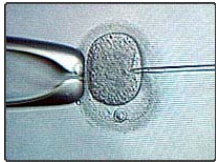
- Unjust attitudes are bad because of their effects and bad in themselves
- Thus we should give priority to correcting them, rather than disability they cause
- But are all reductions in well-being caused by unjust attitudes?

Realistic Conditions



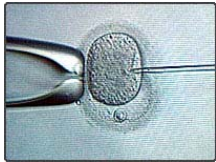
- It cannot be that prejudice exists just in case there is a *conceivable possible* world in which a putative disability has no effect on well-being.
 - ❖ Paralysis may not make a difference to well-being if we all possess powers of levitation and telekinesis.
 - ❖ Being deaf or mute would make little difference if we were all telepathic or everyone was taught to sign
- For something to count as a prejudice it must be the case that there is some *realistic possible* situation, where having X wouldn't reduce S's well-being (McMahan and Fortune)

Example of Prejudice



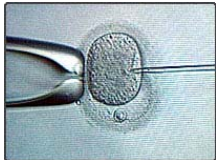
- Anita Silvers points out how a simple change in automobile styles has affected the mobility of people who need wheelchairs to move:
 - ❖ [I]f two-door sedans are available, an individual with a folding wheelchair can drive independently, pulling the chair into the car behind the driver's seat. But the design of four-door cars precludes this maneuver. Consequently, the rarity of the once common two-door automobile has attenuated the mobility of many wheelchair users who can get into a two-door but not a four-door car

Distributive Justice and Prejudice



- BUT the very fact that a person's well-being is reduced because of her social environment—because of the beliefs, attitudes and behaviour of others, and because of the structure and distribution of resources in her society—doesn't yet show that this person is discriminated against.
- For there to be prejudice, these beliefs, attitudes and social arrangements also need to be *mistaken* and *unjust*.

Distributive Justice



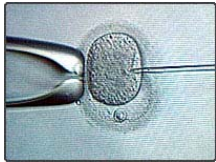
- In order to claim that *all* disability is the result of prejudice, we would have to show that all social arrangements which fail to promote everyone's well-being equally is unjust.
- We would have to accept:

Absolute Welfare Equality (or some other theory of Justice)

Any social arrangement which results in some members of a society having, through no fault of their own, less welfare than others is unjust

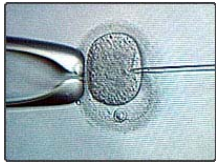
- But this is a very implausible principle of distributive justice
 - ❖ Tall people
 - ❖ Gulliver and Lilliputians

Distributive Justice



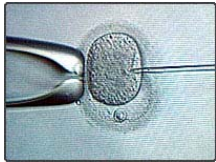
- Some failures to socially correct the harmful effects of some biological or social trait are JUST
- The point of this example is the rather banal one, often ignored by advocates of the Social Model, that not all reduction of well-being due to social factors amounts to discrimination – amounts to Discriminated Trait or disabilitySM.
- The very label of the ‘Social Model’ embodies this conflation. A better label would be the ‘Social Injustice Model’.

Relation to Disease



- Disease may be a deviation from species-typical normal function (SN)
- Disease is important in so far as it constitutes a disability, insofar as it reduces well-being
- Disability is a concept of central concept of health care delivery

One Final Account: Ability, Inability, Disability



- The everyday notion of disability refers to a lack of ability
 - ❖ The blind cannot see, the deaf cannot hear, etc.
 - ❖ If these conditions tend to reduce well-being, they do so, presumably, by depriving those who suffer from them from certain abilities.
 - Their lives don't go as well as they could because there is a range of things that they can't do.
 - ❖ Pain and disease are not disabilities, in this sense, but their effects can be disabling, and therein lies an important part of their badness

Disability_a

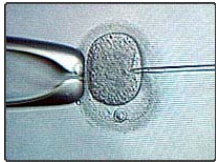
A stable intrinsic property of subject S that prevents S from Ving (in circumstances C)

Inability



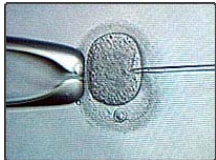
- Disability is definition of *inability*
 - ❖ But very few of these ‘inabilities’ matter.
 - ❖ Being unable to wiggle one’s ears isn’t a disability.
- We *could* define a notion of **disability_{W+a}** which would refer to stable condition that tends to reduce well-being *and* does so because its existence prevents the person from having a range of abilities.

Problems



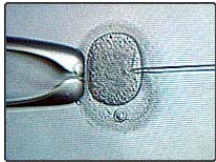
- If lacking certain kinds of abilities or modes of ‘functioning’ was all there was to well-being, then disability_{W+a} would simply follow from disability_W plus this substantive view about well-being.
 - ❖ But as this is an extremely implausible view—a view that leaves no space, for example, for the intrinsic value of pain or knowledge or longevity.
 - ❖ Depression counts as a disability_W not only because depressed people may find it harder to engage in various activities but also because depressed people are disposed to *feel bad*. And lack of an ability can contribute to well-being.
- For those who are addicted to alcohol or who cannot control their urge to eat, it may be a benefit to take substances or have surgery that restricts their ability to act on these harmful urges.

Disability_W or Disability_{a+W}?



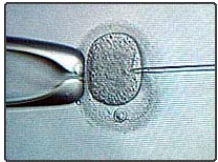
- Disability_{W+a} is too narrow
 - ❖ It fails to single out any interesting normative category.
 - ❖ Lack of an ability is likely to affect one's well-being in a vast number of ways, through different causal routes.
 - no good reason, except the desire not to offend semantic intuitions, to narrow down the welfarist account in this way.

Application



- Case 1 Deafness – deafness is a disability. Except where established deaf projects that give meaning to life
- Case 2. Dwarfism – probably
- Case 3. Body Integrity Identity disorder – surgery is an enhancement
- Case 4. Ashley Case – Ashley Treatment is an enhancement
- Case 5 Colour Blindness – severe disability
- Case 6. IQ reduction – small disability
- Case 7. Cynthia
 - ❖ Not a disability
 - ❖ Like a discriminated trait – result of voluntary deployment

Conclusion



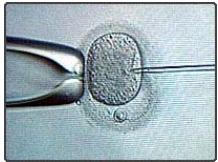
- If we want the welfarist account to most closely overlap the existing concept, we could formulate it to include the threshold limit, the relation to lack of ability, and the subtraction of the effect on well-being due to prejudice, giving us



Disability_{W+a-DT}

A stable physical or psychological property of subject S that (1) leads to a *significant* reduction in S's level of well-being in circumstances C, (2) where that is achieved *by* making it impossible or hard for S to V, and (3) where the effect on well-being in question *excludes* the effect that this condition has that is due to prejudice against S by members of S's society

Conclusion



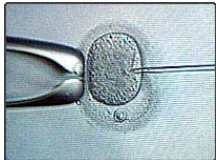
- Since the constraint on ability is not in itself of normative significance, our own preference is for a broader, more inclusive notion:

Disability_{W-DT}

A stable physical or psychological property of subject *S* that tends to reduce *S*'s level of well-being in circumstances *C*, *excluding* the effect that this condition has on well-being that is due to prejudice against *S* by members of *S*'s society due to the deviation of this property from the normal functioning of the species to which *S* belongs

Program on Ethics and the New Biosciences

Change Society, Not People



- We should alter social arrangements to promote well-being, not biologically alter people
 - ❖ *Improve society not enhance people to increase well-being*
- Related: “disability is socially constructed”
- Response:
 - ❖ “Biopsychosocial fit”
 - ❖ We should consider all modifications, and choose the modification, or combination, which is best
 - Skin colour
 - Social modification and discrimination
 - Biological modification and environmental risk

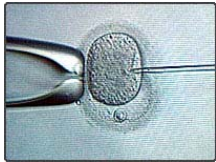


Social Not Biological Enhancement



- **Good Reasons to Prefer Social Rather Than Biological Intervention**
 - ❖ If it is safer
 - ❖ If it is more likely to be successful
 - ❖ If justice requires it (based on the limitations of resources)
 - ❖ If there are benefits to others or less harm
 - ❖ If it is identity preserving
 - ❖ *BUT VICE VERSA*

Social Construction of Disability

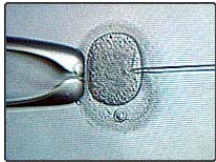


- Disability is socially constructed when there are good reasons to prefer social intervention than direct biological or psychological intervention.
- Biopsychosocial construction of disability:
 - ❖ Must consider reasons for and against intervention at all levels:
 - Social
 - Psychological
 - Biological

~~— whether the modification will harm others or create or exacerbate~~



Conclusion



- There are 4 ways to promote human well-being. Change:
 1. Natural environment
 2. Social environment
 3. Psychology
 4. Biology