Inequity in Maternal and Newborn Health Outcomes in Sweden—What's the numbers and beyond?

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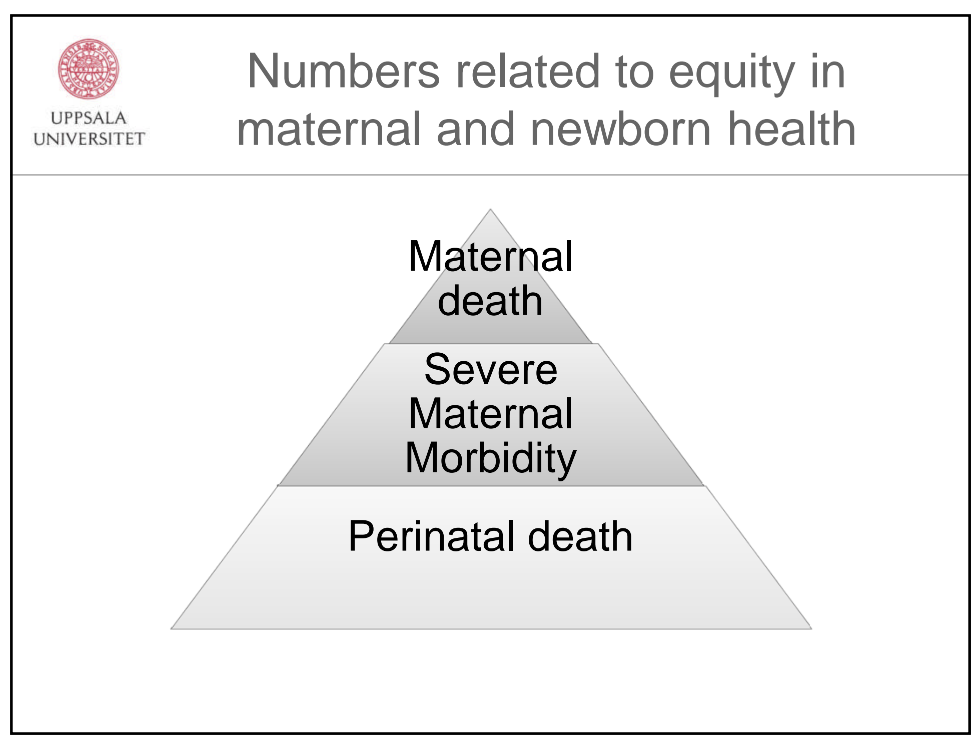
Perinatal outcome of migrant women and integration policy

- ”Overall, as compared to natives, immigrant women showed a clear disadvantage for all outcomes: 43% higher risk for low birth weight, 25% preterm delivery, 50% perinatal mortality and 61% malformations. **The risks were clearly and significantly reduced with a strong integration policy**”
- ”The mechanisms through which **integration policies** may be protective include increased participation of immigrant communities, decreased stress and discrimination”

Bollini et al. Soc Sci Med , 2009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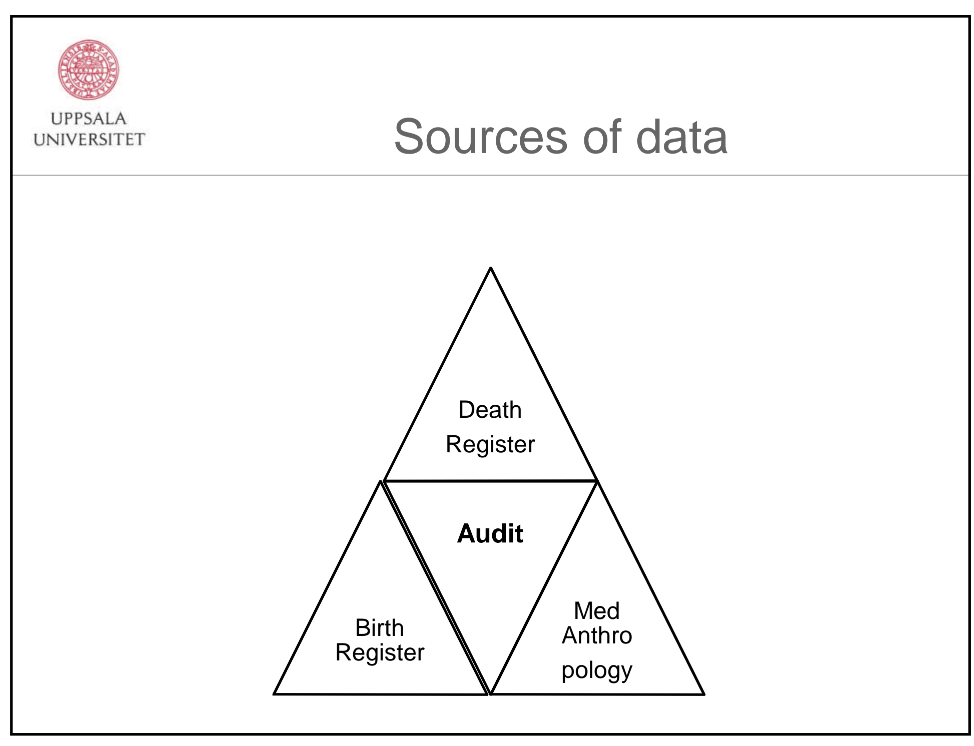
Numbers related to equity in maternal and newborn health
Maternal death
Severe Maternal Morbidity
Perinatal death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Sources of data
Death Register
Audit
Birth Register
Med Anthro pology

Definition of material and population? ”Minority ethnics” and other impossible concepts

Definitions

Immigrants
Ethnicity
Etnic background
Race
Foreign-born
Nationality
Low-/High-Income Country
Minority ethnics
Multi-cultural

Both parents?
Dynamic but undefinable
Self definition? UK
Discrimination? USA
Registers? SWE
Stateless?
Socio-economic status?
How are the Majority?
Religous beliefs?
culturalism?

Outcome from Register data
Death numbers among ”Black Africans”

Pregnancy relat mortality	• RR 6.6 (2.6 -16.5)
Severe maternal morbid	• OR 2.3 (1.9–2.8)
All LIC/ Somali Near miss	• 2.1/ 9.1 per 1000 deliveries
Perinatal mortality	• OR 4.4 (2.1-8.3)
”FGM/Circumcised”	• Aprox 98%
”Refugees”	• Aprox 100%

Essén et al 2000, Esscher et al 2012, Wahlberg et al 2013

PERINATAL OUTCOME
(Swe=10 784) (African=356)

	Sweden	**Africa**	Relative Risk
Perinatal mortality	65	9	**4.2** (2.1-8.6)
Small Gest. Age	150	10	1.8 (1.0-3.6)
Apgar Score (<7 5´)	148	13	2.5 (1.4-4.4)
Intensive Care	766	21	0.8 (0.5-1.3)

Essén et al. Acta Obst Gynecol Scand 2000:79.

Interconnected themes relevant to equity in health and health care

Equity in

(1) health status outcomes

(2) access to health care services

(3) delivery of health care services

(4) policy and financing of health care systems

ROAM , A Gagnon et al
2011

The numbers
Mortality and Near miss

Esscher et al.

Excess mortality in women of reproductive age from low-income countries: a Swedish national register study. *Eur J of Public Health,* 2012

Esscher et al.

Maternal mortality in Sweden 1988–2007: More deaths than officially reported. *Acta Obstet Gynecol Scand*. 2013

Wahlberg et al.

Severe Maternal Morbidity "near miss" in Sweden 1998-2007 – are there differences between women from high and low-income settings? *BJOG 2013*

Fernbrant et al.

Interpersonal violence as cause of death in foreign-born women of reproductive age : A Swedish population-based study. Submitted.

Beyond the numbers
Barriers for access & delivery of care

Binder et al.

Conceptualising the prevention of adverse obstetric outcomes among immigrants using the 'three delays' framework in a high-income context. *Socl Sci of Med 2012*

Esscher et al.

More substandard of care among immigrant maternal deaths than natives, a Swedish maternal audit study 1998-2010. *Submitted* 2013.

Essén et al.

Exploring family experiences of care after maternal death in Sweden: Interview study with relatives from Africa's Horn, 2004-2012. *Ms*

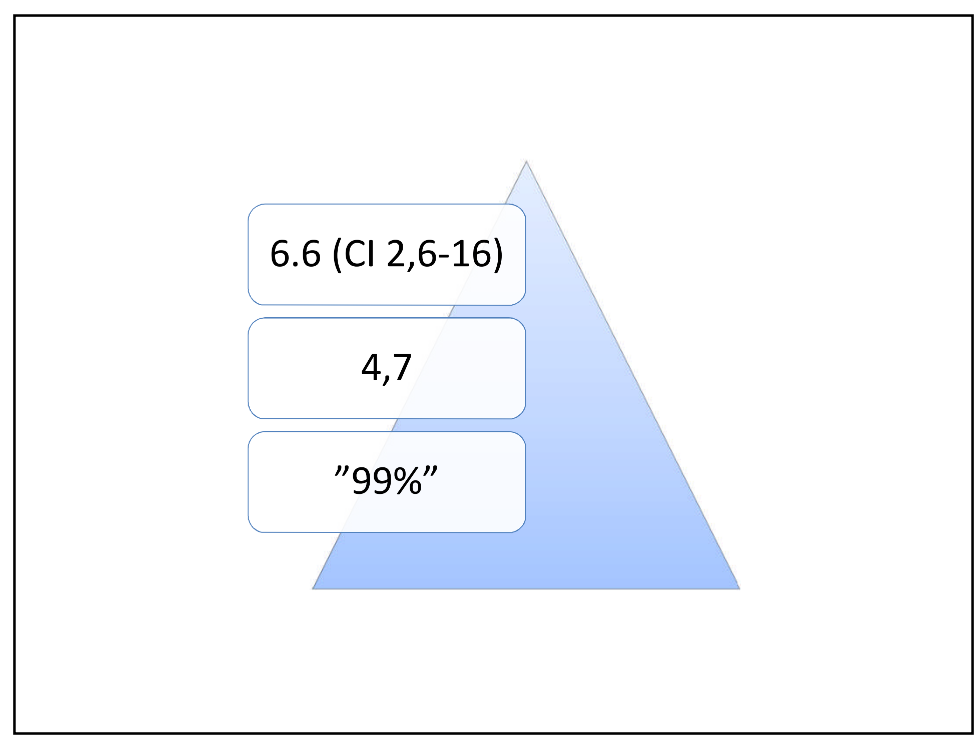
Populations where there are NO numbers…

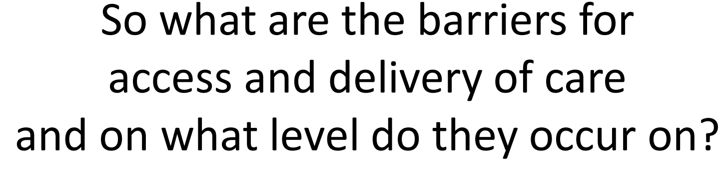
Counting the non-existing deaths. A mortality study among undocumented residents in Sweden, 1997- 2010.

Prel findings:

1 200 asylum seekers:

- 25% real undocumented
- 1 maternal death
- 3% < 18 yrs


6.6 (CI 2,6-16)
4,7
”99%”


So what are the barriers for
access and delivery of care
and on what level do they occur on?

Material and audit method

A group of senior experts reviewing medical records, asses sub-optimal factors – A major factor if it contributed significantly to death and if different management would have likely avoided the outcome.

Perinatal audit: All 62 East African cases in 1990-1996
matched 124 Swedish-born

Maternal audit: All 25 from low-income countries 1988-2010
matched with 50 Swedish-born

Contributing factors to death identified by the modified three delays model and the maternal migrant effect for each of the three levels:

1) socioeconomic/cultural factors of the patient and her family
2) accessibility of service
3) quality of medical care.

(Binder, Johnsdotter, Essén. Soc Sci Med, 2013)

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The 3 Delays Level Model modified for migration

1. Socioeconomic/cultural factors of the patient and her family
2. Accessability to adequate service
3. Quality of medical care

(Too far to walk, Thaddeus & Maine, Soc Sci Med, 1994
and Binder, Johnsdotter Essén.al Soc Sci Med, 2013)

Not too far to walk for immigrant women but too far for reciprocity at facility level:

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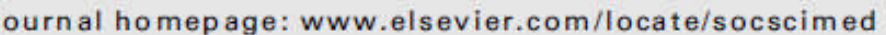

Conceptualising the prevention of adverse obstetric outcomes among immigrants using the 'three delays' framework in a high-income context

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[b] Faculty of Health and Society, Malmö University Hospital, Malmö, Sweden

Major contributing factors to death: 1) Socioeconomic/cultural factors

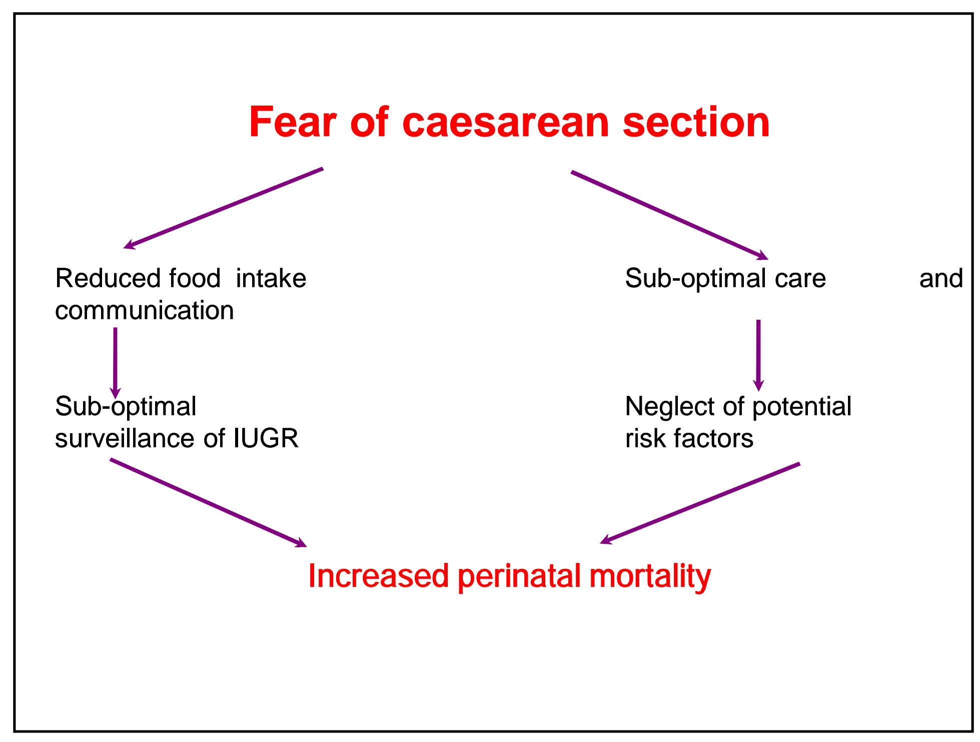
	Perinatal Deaths N=62/124	Maternal Deaths N=25/50
Non-compliance	9/0*	6/4*
Refusing cesaearan sectio	5/0*	0/0
Late/non-booking	0/0	0/0
Unhealthy lifestyle	0/10*	0/3
Religion/gender	0/0	0/0

Major contributing factors to death: 2. Accessability to service

	Perinatal Deaths N=62/124	Maternal Deaths N=25/50
Misscommunication patient and provider	5/0*	14/0*
Miscommunication bwn providers	0/0	5/4
Delayed transport	0/0	0/0
Incomplete legal status	0/0	0/0

Major contributing factors to death: 3. Quality of medical care

	Perinatal Deaths N=62/124	Maternal Deaths N=25/50
Inadequate care	20/9*	21/28*
Delay referral		10/14
Low priority of resources	0/0	2/0
Lack of managemnt of FGM	0/0	0/0



WHY AVOIDING EMERGENCY C/S DUE TO FETAL ASPHYXIA?

28 years, primigravida

4.00	Vaginal bleeding, abdominal pain. CTG pathological signs. Preparing C/S
4.15	Patient refuse vaginal examination
4.30	Patient refuse C/S
4.40	Foetal heart rate <80. The doctor tries to explain the emergency situation but the patient and husband do not understand, verbal miscommunication
4.50	The woman accepts C/S
5.00	Intrapartal death. Apgar 0-0-0. Abruption of placenta

EXPERIENCE OF MATERNAL DEATHS

"In this country, I heard one lady that died after delivery but I don't know why. In Somalia, not just in Somalia but in all African countries, women die all the time.

There have been a lot, but in this country I just heard one, really, "….." I was really very worried because, the time you are pregnant, if it happened in Somalia, you are on the curse between life and death. You don't know what is going to happen to you, that is what the old women, like my grandmother, told me. That is a common word in Somalia. "

Somali women, 5 yrs in UK, 1/4 children by C/S

Barrier:
Different perception of care

"When they took me to the theatre for caesarean , the water broke and the baby was delivered in the normal way. What did I say? To all my friends I now say: Do not go to the hospital! Stay home! It is like a rule here in England that they do caesarean. All doctors do the same…… "

I: Couldn't it be dangerous to wait too long?

" The doctors are liers. They are telling us when they want to do the caesarean that there is no heartbeat, but then the baby is delivered with normal heartbeat . They are lying all the time!!

Somali women, London

"How do you deal with somebody who is not in control of their own health needs?"

West African consultant, London

DOCTOR'S DELAY

Lack of awareness of these circumstances among care providers could be linked to sub-optimal care resulting an increased perinatal mortality.

(B Essén et al, BJOG 2002, Essén 2012)

The prevailing discourse
(from policymakers or sytematic reviews)
of how to reduce barriers for equity in reproductive health

”Be more cultural sensitive & competent”

”Impove accessabiliy for refugees”

”Maternal and perinatal mortality is due to FGM/circumcision” (WHO, Lancet 2006)

How to reduce the barriers?

The prevailing discourse
(policymakers or sytematic reviews)

- ”Be more cultural sensitive & competent”
- ”Impove accessabiliy for refugees”
- ”Maternal and perinatal mortality is due to FGM/circumcision” (WHO, Lancet 2006)

Action based on Audit results

- Be more social competent
- Improve communication interpreter service
- Give same medical care independently ethnic background but listen to the patient
- Discriminataion? If so -how to meassure??

Kejsarsnitts-paradoxen

”I noticed that there were actually no care plans or guidelines… even if you are aware of these women who refuse Caesarean section. However, there [is not much discussion about] how to resolve the problem… It seems to be handled more like a cultural problem, private problem, their own business…”

Förlossningsöverläkare, London 2006

PERINATAL OUTCOME

	Sweden (n=10 784)	**Africa** (n=356)	Relative Risk OR (CI)
Perinatal mortality	65	9	4.2 (2.1-8.6)
Small Gest. Age	150	10	1.8 (1.0-3.6)
Apgar Score (<7 5´)	148	13	2.5 (1.4-4.4)
Intensive Care	766	21	0.8 (0.5-1.3)

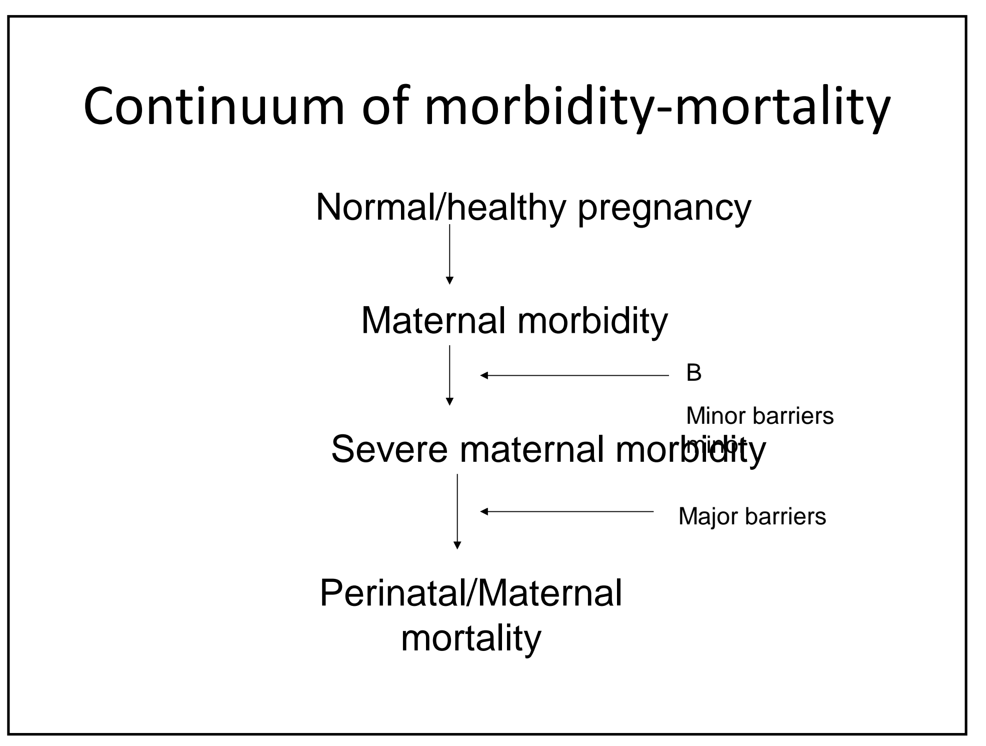
Essén et al. Acta Obst Gynecol Scand 2000:79.

Sub-optimal factors	**Somali (62)**	**Swedish (113)**
Medical care factors		
Insufficient foetal surveillance	4	2
Inadequately given medication to mother or premature infant	10	6
Misinterpretation of CTG	6	1

Essén et al BJOG, 2002:109

Sub-optimal factors	Somali (62)	Swedish (113)
Maternal factors		
Placental abruption, smoking , SGA	0	10
Delay in contact with health care when needed or non-participation in clinical routines	9	0
Mother avoiding caesarean section	**6**	0
Communication		
Verbal miscommunication	**5**	0

Essén et al BJOG, 2002:109



Framework for equity in health and health care (enl ROAM)

Gagnon et al 2011 forthcoming

Material and method

Interviews: in-depth individual and focus group

- Greater London, UK, 2005-2006 and Sweden 2010-11
- Snowball sampling and purposive sampling, Culture brokers and interpreters
- Around 55 Somali & 20 other ethnic African or Caribbean mothers
- 62 ethnically diverse obstetric care providers
- Framework of naturalistic inquiry analysis of text data *(Lincoln and Guba, 1985)*

Maternal audit 1988-2010

- 26 maternal deaths from low-income countries matched with 48 Swedish-born,
- Suboptimal factors were identified and categorized, with the framework of the modified three delays model and the maternal migrant effect for each of the three levels:
  1) socioeconomic/cultural factors of the patient and her family,
  2) accessibility of facilities factors
  3) quality of medical care.

*defined as country of origin

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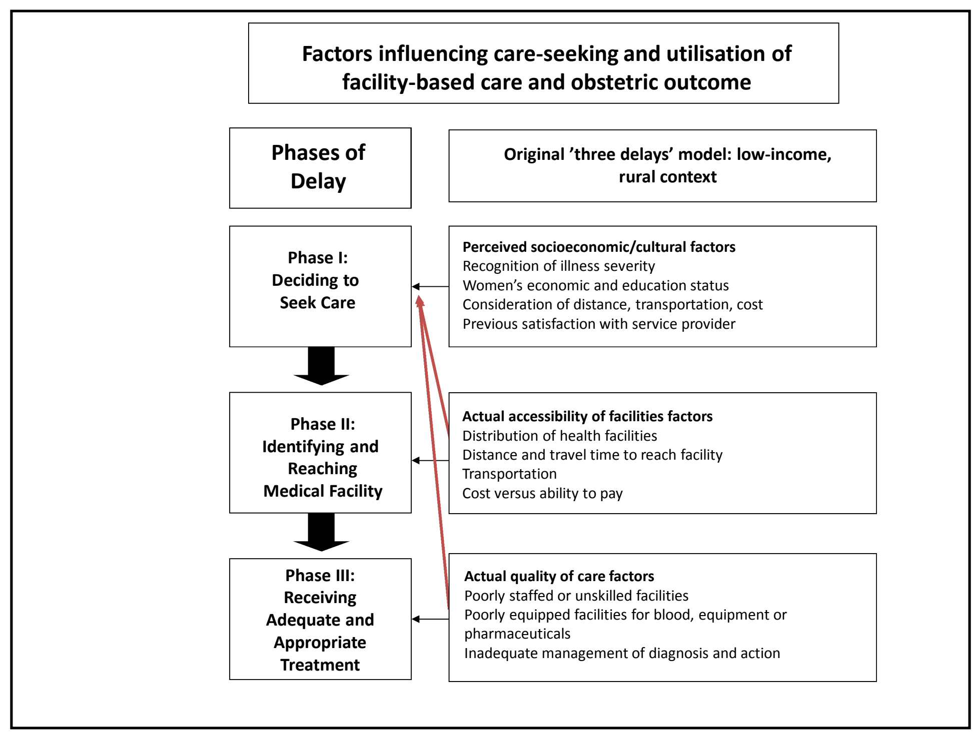


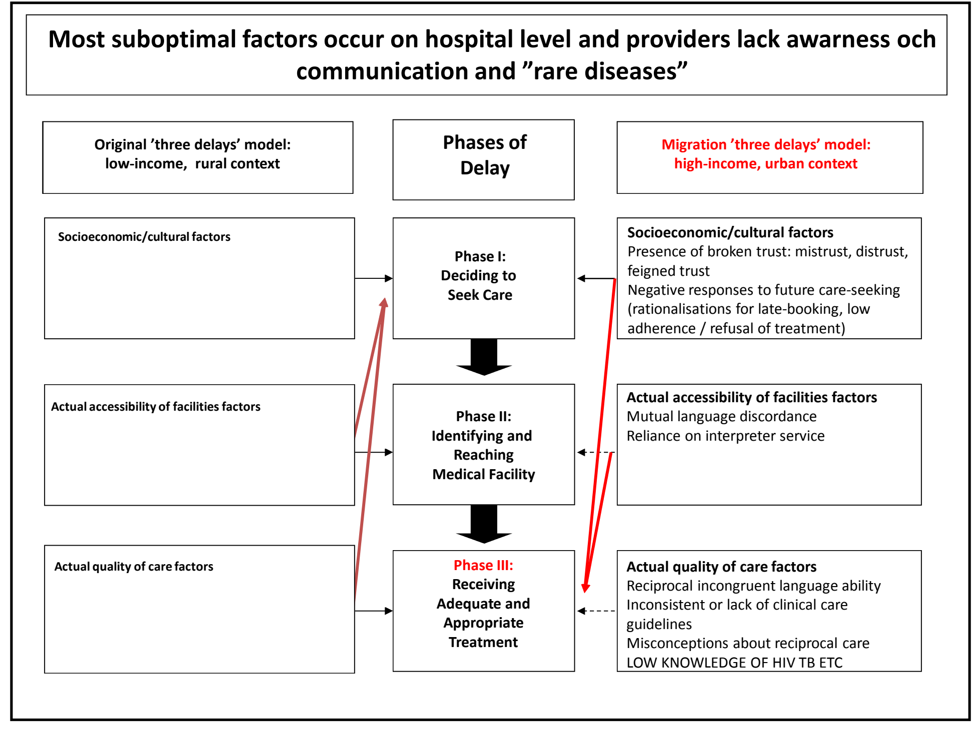
Suboptimal factors	Foreign-born (N = 25)	Swedish -born (N = 48)	P
Sociocultural factors	11	7	0.01
Non-comliance	6		
Late booking			
Un-healthy lifestyle	0	3	
Accessibility of services	14	0	
No Interpreter	13	0	
Misscom bwn providers	5	4	
Incomplete legal status	1	0	
Delayed transport	1	0	
Quality of medical care	21	29	0.04
Inadequate care	21	28	0.03
Delay in referral	10	14	ns
Appr. care but too late	5	11	ns
Limited resources	3	3	ns

Phase 2 delays: Barriers to accessibility/infrastructure?

Hypotheses	Actual barrier by audit
All women knew how to access emergency help via NHS	**No barrier**
Transportation	**Limited barrier**
Cost	**No barrier**
Discordant language/miscommunication	**Major barrier**
Suboptimal interpreter service	**Major Barrier**

Phase 2 suboptimal interpreter service influences phase 3 receipt of adequate care

Explanatory factor: actual miscommunication explains perceived lack of trust and actual poor quality of care at facility level



Phase 3 delays: Barriers related to receipt of optimal care

Phase 1 barriers to decision for care-seeking	Choice-making barriers
Phase 2 barriers discordant communication and suboptimal interpreter service	Management barriers
Providers ascribe problems in care provision to women	Reciprocal lack of trust
Women's autonomous strategies are preferred over western obstetrics care	Dissociation from NHS
Broken social networks in new setting	Anti-social capital

Explanatory factor: lack of acceptance of obstetrics-based knowledge in migration context and poor recognition of context-based obstetrics care are two explanations for adverse outcome

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Beyond the death numbers by confidential enquiry/audit method

Maternal mortality global perspectives

	Somalia	Sweden
Maternal deaths	1,600	3
Life expectancy (yrs)	43	80
Infant mortality	131	6
Population coverage of health services (%)		
Urban	50	100
Rural	15	100
Female adult literacy (%)	6	100
Safe water (%)		
Urban	60	100
Rural	20	100
GNP/capita (US$)	290	19,300

Death register, MBR

1988-2007,1998-2009, 1996

The
maternal mortality ratio in Sweden, was 3.6.
After linking registers and reviewing death certificates, we identified 64% more maternal deaths, resulting in a ratio of 6.0 (or 6.5 if suicides are included).
The
pregnancy-related mortality ratio was 7.3. A total of 478 women died within a year after
being recorded with a diagnosis related to pregnancy.
Conclusions: By including the 123
cases of maternal death identified in this study, the mean maternal mortality ratio from 1988–
2007 was 64% higher than reported to the World Health Organization.

Different ”death numbers”

Pregnacy related mortality RR 6.6 (CI 2.6 -16.5)

Maternal near miss OR 2.3 CI 1.9–2.8

Perinatal moratality OR

Esscher et al 2012, Wahlberg et al 2013, Essén et al 2000.

The numbers

- **Död i reproduktiv ålder pga**
- **Infektionssjukdomar**
- RR 15.0 (CI 10.8-20.7)
- **Graviditetsrelaterade sjukdomar**
  - RR 6.6 (CI 2.6 -16.5)
- *Esscher et al. Forthcoming 2011*

- *Probe into maternity unit deaths*
- *"The government has ordered special measures be introduced at a maternity in north west-London over concerns at the high number of women's death. The move comes after an investigation at the hospital revealed "serious system failures".*

(BBC News 2005/04/21)

SvD Utrikes *(23 augusti 2006)*

"Under tre år har tio kvinnor avlidit på en BB-avdelning i nordvästra London på grund av dålig organisation, otillräckliga resurser och brister i systemet."

Why differences in perinatal outcome?
Essén's framework

1. Sociodemographic background - *women*
2. Pre-pregnacy illness -*women*
3. Suboptimal care - *provider*
4. Accessability – *illegal women*

5. Misscommunication - *women & provider*
6. Different perception of care
   -*women & provider*

Metodutveckling

-
- 3 Delays Model: *Migration*
- Audit: *MM, MNM, MNM+CS (LIC/Migration)*
- Qual Content Analysis vs Naturalistic Inquiary

In Short ...

Once a woman is pregnant
most serious obstetric complications
cannot be predicted or prevented,

but they can be treated.

So

all pregnant women
need access to
emergency obstetric care

RH-Safe motherhood

- Mödradöd — Socioekonomi (MDG 5)
- Near Miss — vårdkvalité/SES?
- Perinatal död — vårdkvalité

Inequity in RH Essén's framework

1. Sociodemographic background - *women*
2. Pre-pregnacy illness -*women*
3. Suboptimal care - *provider*
4. Accessability – *illegal women*
5. Misscommunication - *women & provider*
6. Different perception of care -*women & provider*

Beyond the numbers

- Some social but not cultural nor religious factors related
- Poor accessibility only due to misscommunication
- Type of sub-optimal medical care?
- FGM/circumcision not related
- Discrimination?

Erfarenhet av mödradöd från hemlandet

(resultat beskrivet av kvinnan)

"In this country, I heard one lady that died after delivery but I don't know why. In Somalia, not just in Somalia but in all African countries, women die all the time.

There have been a lot, but in this country I just heard one, really, "….." I was really very worried because, the time you are pregnant, if it happened in Somalia, you are on the curse between life and death. You don't know what is going to happen to you, that is what the old women, like my grandmother, told me. That is a common word in Somalia. "

Somali women, 1/4 children by C/S

- Religion sex preference of provider
- Eklampsi
- No home deliveries
- No undocumented refugee but
- FGC not related to MM
- Kommunikation det övergripande
- Accessibility något annat
- Diskriminering?

Resultat beskrivet av forskaren

DOCTOR'S DELAY:

Lack of awareness of these circumstances among care providers could be linked to sub-optimal care resulting an increased perinatal mortality.

(B Essén et al, BJOG 2002)

Kan jag testa denna hypotes?

Perinatal audit

Suboptimal factors	Foreign-born (N = 25)	Swedish -born (N = 48)	P
Sociocultural factors	11	7	0.01
Non-comliance	6		
Late booking			
Un-healthy lifestyle	0	3	
	14	0	
Accessibility of services			
No Interpreter	13	0	
Incomplete legal status			
Delayed transport	1	0	
Quality of med care			
Inadequate care			
Misscom bwn providers			
Delay in referral			
Appr. care but too late			
Limited resources			

Suboptimal factor	Foreign-born (N = 25) Cases with suboptimal factors (major + minor)[1]		Swedish-born (N = 48) Cases with suboptimal factors (major + minor)[1]		p value
Total	**22**	**(15 + 7)**	**29**	**(21 + 8)**	**0.01**
Care-seeking	**11**	**(1 + 10)**	**7**	**(5 + 2)**	**0.01**
Non-compliance	6	(1 + 5)	4	(2 + 2)	
Late-/non-booking	5	(0 + 5)	0		
Unhealthy lifestyle (substance abuse)	0		3	(3 + 0)	
Accessibility of services	**14**	**(3 + 11)**	**0**		
Limited language congruence	13	(3 + 10)	0		
Incomplete legal status[2]	2	(0 + 2)	0		
Delayed transport	1	(0 + 1)	0		
Quality of medical care	**21**	**(15 + 6)**	**29**	**(19 + 10)**	**0.04**
Inadequate care	21	(14 + 7)	28	(17 + 11)	0.03
Delay in consultation or referral[3]	10	(8 + 2)	14	(8 + 6)	0.2 ns
Appropriate care, but too late	5	(4 + 1)	11	(7 + 4)	0.8 ns
Miscommunication between providers	5	(3 + 2)	4	(2 + 2)	0.2 ns
Limited use/priority of resources[4]	2	(1 + 1)	3	(0 + 3)	0.8 ns

Suboptimal factor	Foreign-born (N = 25)		Swedish-born (N = 48)		
	Cases with suboptimal factors (major + minor)[1]		Cases with suboptimal factors (major + minor)[1]		p value
Total	**22**	**(15 + 7)**	**29**	**(21 + 8)**	**0.01**
Care-seeking	**11**	**(1 + 10)**	**7**	**(5 + 2)**	**0.01**
Non-compliance	6	(1 + 5)	4	(2 + 2)	
Late-/non-booking	5	(0 + 5)	0		
Unhealthy lifestyle (substance abuse)	0		3	(3 + 0)	
Accessibility of services	**14**	**(3 + 11)**	**0**		
Limited language congruence	13	(3 + 10)	0		
Incomplete legal status[2]	2	(0 + 2)	0		
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Limited use/priority of resources[4]	2	(1 + 1)	3	(0 + 3)	

"Top 10 Recommendations"
Migrationsperspektiv

1. Preconception care (HIV, hjärtsjd)
2. Professional interpreter for all
3. Communication and referrals (gemensamma möten)
4. Multidisciplinary specialist care
5. Basic clinical skills,training (praktik utomlands ST)
6. Identify and manage very sick women (akutmedicinare gynkunskap)
7. Prevent/recognise/treat sepsis
8. Audit –våld svårast förstå
9. Quality pathology (överlåt ej problemet till anhöriga)

-
- *Saving Mothers lives 2011/modifierad Essén 2011*

The importance of cultural factors?
Different perceptions: Somalis vs health providers

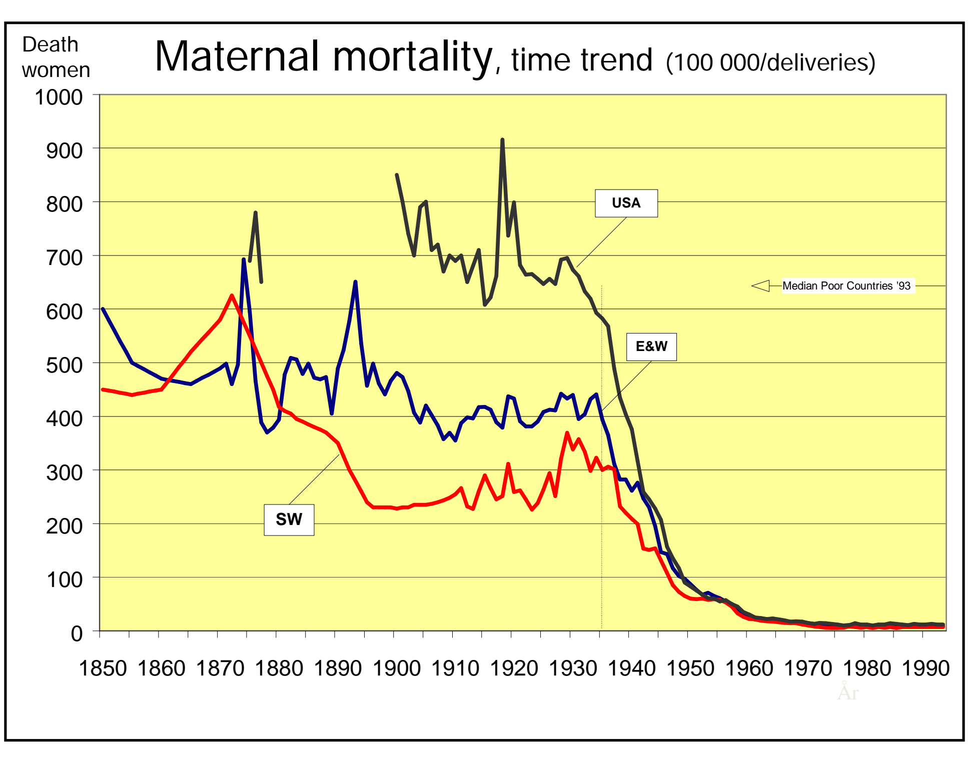
- **Professionalism and individualized care** were of more importance than being treated by providers from one's own ethnic group.
- **Religion**, as an important issue for women when making medical decisions was brought up by the health providers, --a claim that was **not** confirmed by the care seekers.
- **The sex of the obstetrician and the husband's role** regarding communication were interpreted by health care providers in a different way than by the women themselves; a discrepancy that might be a source of misunderstandings.
- *Binder P, Borné Y, Johnsdotter S, Essén B. Shared language is essential: Communication in a multie-ethnic obstetric care setting. J of Health Communication: International Perspectives 2012*

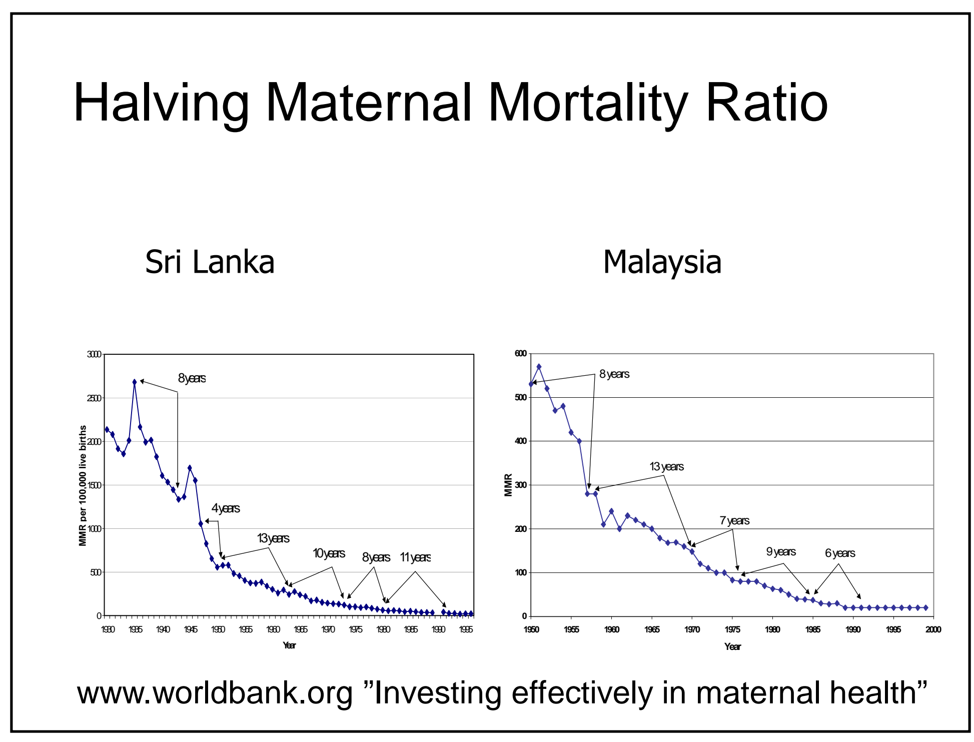
The importance of cultural factors?
Different perceptions: Somalis vs health providers

- **Language** seems to be of more importance than meeting providers of the same ethnic group.
- **Professionalism and individualized care** were of more importance than being treated by providers from one's own ethnic group.
- **Religion**, as an important issue for women when making medical decisions was brought up by the health providers, --a claim that was **not** confirmed by the care seekers!
- **The sex of the obstetrician and the husband's role** regarding communication were interpreted by health care providers in a different way than by the women themselves; a discrepancy that might be a source of misunderstandings.
- **The translation service** seems to be used in a sub-optimal way.
- *(Essén et al, submitted 2010)*

Learning from history

- One nation one flag



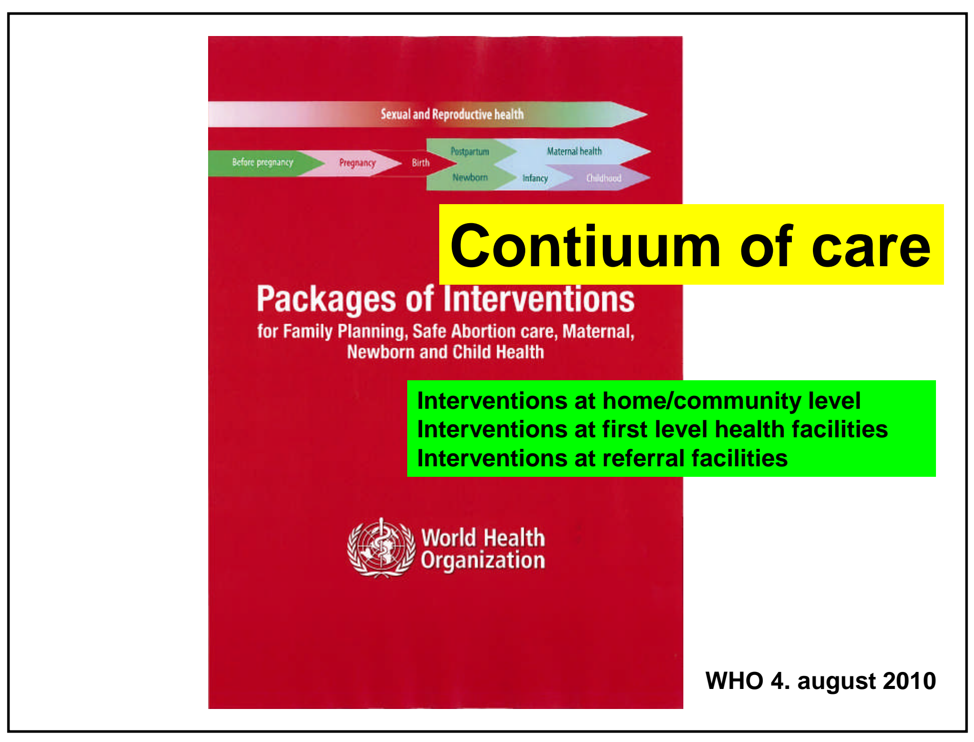


History: Sri Lanka & Malaysia

How did they do it ?

- Expanding access to effective maternity care by midwives and doctors
- Improving utilization and quality of care with emphasis on making life-saving care free.
- Education for girls
- Water and Sanitation

The World Bank, 2003


Sexual and Reproductive health
Before pregnancy
Pregnancy
Birth
Postpartum
Maternal health
Newborn
Infancy
Childhood
Contiuum of care
Packages of Interventions
for Family Planning, Safe Abortion care, Maternal, Newborn and Child Health
Interventions at home/community level
Interventions at first level health facilities
Interventions at referral facilities
World Health Organization
WHO 4. august 2010

UPPSALA UNIVERSITET

Etnisk bakgrund (statiskt)

"Från en kurdisk familj", "har judisk bakgrund", "är av samisk släkt"…

Etnicitet (dynamiskt)

Primordialism: Gräsrotskänslor, starka band av samhörighet utifrån släktaskap (*kinship ties*), etnicitet ärvs och är central för identiteten – därför etniska konflikter.

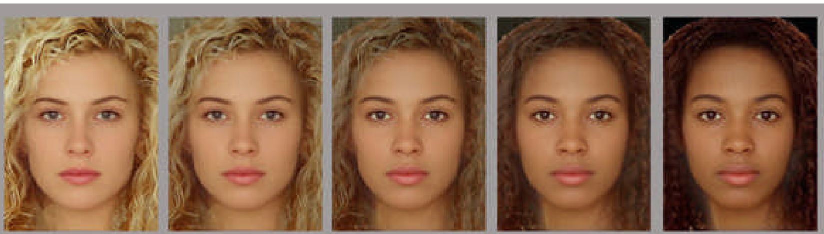
Instrumentalism: Etniska konflikter är inte "djupt rotade" eller oundvikliga – de uppstår efter eliters manipulationer.

Ras

Socialt konstruerat, ej biologiskt grundat längre

Används flitigt i bla USA och England (jfr vår användning av **etnisk bakgrund/etnicitet**).

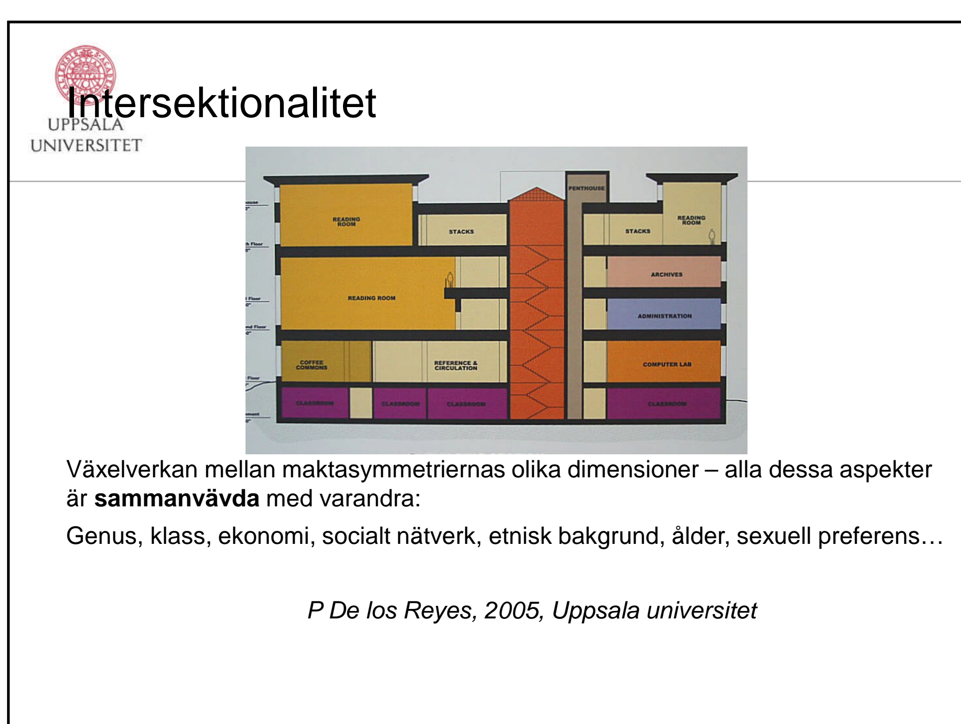
Används inte gärna i t ex Frankrike, Sverige och många andra icke-engelsktalande länder.



Kultur

- Alla människor är kulturella varelser
- Föreställnings- och värderingssystem som inverkar på praktiker, normer, sociala institutioner, etc

- Kultur är flytande och dynamiskt (ett verb: vad man GÖR, inte ÄR)



Intersektionalitet

Växelverkan mellan maktasymmetriernas olika dimensioner – alla dessa aspekter är **sammanvävda** med varandra:

Genus, klass, ekonomi, socialt nätverk, etnisk bakgrund, ålder, sexuell preferens…

P De los Reyes, 2005, Uppsala universitet

- *Mångkulturella samhällen*
  -- empiriskt faktum

- *Mångkulturalism*
  -- ideologi, politisk agenda